

‘FORGOTTEN SHOPPING, LOST KEYS AND
HEARTS WHICH FORGET TO BEAT’:
AN EXPLORATION OF NURSES’
CONCEPTUALISATION OF DEMENTIA

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Thesis presented in fulfilment of the requirement of the degree of Doctor
of Philosophy

THE UNIVERSITY OF EDINBURGH

2010

ABSTRACT

This thesis explores nurses' conceptualisation of dementia and discusses the relationship between these understandings and nursing practice. Using the reflexive sociological approach of French scholar Pierre Bourdieu, the study seeks to advance practice through the enhancement of theoretical understandings. Data were collected in a range of inpatient clinical areas in Scotland using focus groups, individual interviews and observation. A range of nurses contributed, reflecting views and understandings from inpatient areas run by both general medical and mental health services.

Nurses were found to conceptualise dementia in four main ways; as a disease, as a memory problem, as confusion and finally as a journey. These four conceptualisations are addressed in turn and the ways in which they inform and relate to practice are discussed. Limitations to practice arising from the nurses' conceptualisations are also highlighted. Dominant approaches to care are outlined throughout the thesis, with the medical model, individualised care, person-centred dementia care and palliative care all being discussed in light of the nurses' understandings of dementia.

Throughout the thesis the work of Pierre Bourdieu shapes the analysis and presentation of data. Relationships within the social world, structures of society and of inpatient settings along with explicit reflection on the personal experiences and position of the researcher inform the work. Concepts of field, capital and habitus permeate the discussion and help to explore issues and understandings from both practice and theory.

While literature on specific approaches to dementia care, treatments and relationships between patients, carers and family members form a substantial and growing body of dementia literature, information about nurses and their understandings of dementia has previously been unexplored. This study demonstrates the range of views held by nurses and the influences of education, structures of the clinical setting and ward culture in shaping those understandings. The importance of nurses' conceptualisations of dementia in shaping their care of patients is demonstrated through the analysis and has the potential to inform and enhance practice development for dementia patients in a variety of inpatient settings.

DECLARATION

I hereby declare that this thesis has been composed by me and that the research on which it reports is my own work.

Sarah J. Rhynas

December 2009

ACKNOWLEDGEMENTS

I am very grateful to many people for their support throughout the composition of this thesis.

Firstly, I would like to thank the family and nurses who inspired this work and the many nurses who gave so generously of their time in contributing to this study. I would also like to thank Tony Gordon and his 'team' who helped me in pilot focus groups, Sister Simpson and colleagues at the Royal Infirmary of Edinburgh who talked through my early thoughts and questions, encouraging my interest in this topic and in nursing research.

I would like to thank my supervisors, Professor Rosemary Mander and Dr Anne Robertson for their invaluable advice, constant encouragement and patience in the face of missed deadlines, maternity breaks, teething babies and my own constant doubts about my work. I have gained enormously from my meetings with them.

I am grateful to the Gardner Bequest which provided financial support for this study.

To all the past students and friends in 'Number 12' I would like to express thanks for your companionship, encouragement, advice and lengthy academic debate over long lunches. These discussions have stayed with me and provided a unique and wonderful learning opportunity which I did not fully appreciate until it was gone. Thanks also to Steve Tilley, Desmond Ryan and others who joined us for lunch and added so much to the debate.

Last but certainly not least to my wonderful family I can only say thank you for years of support, encouragement and practical assistance. To my Dad whose own PhD was always a fascination to me and who has always been able to understand and encourage my desire to undertake this crazy academic endeavour. To my Mum, who has offered a huge range of support from babysitting and cooking meals to sorting references and proof reading. Grateful thanks are also due to my parents in law for babysitting whenever necessary, often juggling the complicated social lives of my busy young pair!

Finally, my wonderful husband and children. Neil has been unfailingly supportive of an endeavour which he has never purported to understand and which has now extended throughout our married life. My gratitude for his love and support can not be put into words. Between regular childcare, computer support and his putting up with weeks where I was locked in the study from his arrival home from work until well after bedtime, he has always encouraged me to complete this work.

Craig and Lauren have added both delight and distraction to my life! They have provided both impetus to finish this work and endless reasons not to bother! From Lego towers to teething, baby swimming classes to pureeing carrots they have changed my life and my work and are the joy of my life. I have to thank them for coming to the library, keeping quiet at the right moments (sometimes) and putting up with Mummy and her 'boring papers' cluttering up the table which should really be used for tea or play-dough!

Thank you to each and every one of you who have been so important to me throughout this experience.

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CHAPTER ONE

INTRODUCTION

“Despite two or three generations of scholarship, the relationship between the practice of nursing and the conceptual knowledge that is supposed to drive it remains ambiguous and confusing (Thorne 2005 p107).”

This thesis explores the relationship between the practice of nursing and the conceptual knowledge within the area of dementia nursing. The motivation for this work came from nursing practice in acute medical areas and so the findings of the study are intended to meet the needs of both practice and academia. The thesis moves from the hospital setting and the views of practising nurses, through the theoretical abstractions of analysis and returns to the practice setting with a newly generated view of the conceptual knowledge informing nurses in the care they give to those who have dementia. In an attempt to address Thorne’s (2005) concerns regarding ambiguity and confusion, this thesis uses a reflexive sociological approach to ensure the clarity of the relationship between theory and practice and, in turn, informing both areas.

1.1 Background

The impetus for this piece of work came from nursing practice in acute medicine and from a series of experiences, culminating in the admission of a patient whom I have called Sally. I have included the story of Sally in this introduction in order to show

where this project began and to show how apparently simple the questions were in the early days of this work.

Sally

Sally was a 78 year old woman who was seen in the medical outpatient clinic with a three month history of forgetfulness and slight dyspraxia. Her adult children were concerned about the changes in her behaviour and her mood. Two years previously Sally had undergone treatment for breast cancer and in view of this history the medical staff decided to admit Sally to hospital for a CT brain scan in order to identify any brain metastases.

On the day of admission Sally arrived at the hospital with her two daughters and spent some anxious hours on the ward before being taken to the radiology department. The nurses on duty spoke to Sally and her family, outlining the procedure and reassuring the family about the test. I was one of those nurses. During the afternoon handover meeting the nurses talked together about the impending CT scan and expressed their concerns about the potential recurrence of malignancy.

Some time later with the CT scan complete and the results available Sally, her family and her named nurse met with the medical staff in order to discuss the outcome. The scan showed no evidence of brain metastases but did show clear signs of vascular dementia which could account for Sally's symptoms. Sally and her family were delighted to hear that the cancer had not returned. This reaction showed their relief as they reflected on the stress of the previous cancer diagnosis and treatment. The family's reaction made sense to me as a nurse observing the scene. This family had previously undergone the trauma of cancer treatment and currently had no understanding of what the future might hold with a diagnosis of vascular dementia. The nurses, also, celebrated the diagnosis with the family. Thereafter, in the staff room the nurses chatted amongst themselves and reflected on the good results from the CT scan and the relief that they too had felt at the diagnosis of vascular dementia.

As a nurse with an interest in the care of older people living with dementia the reaction of my colleagues interested me. We discussed the symptoms which Sally experienced and talked about how these symptoms might progress through the course of metastatic cancer or vascular dementia. Many similarities were evident. The thoughts of my nursing colleagues were summed up by one nurse who could not understand my reservations about the day's events. She said,

“Well, the dementia’s just a nuisance, you forget your shopping list, door keys, things like that – things could be worse! Cancer’s serious!”

I was left questioning my own understanding of dementia and my view that this was a life changing diagnosis. I wondered if my personal experiences of dementia in my family or my work experience in dementia day care had allowed me to develop a view of dementia which was too catastrophic. Perhaps the nurse who saw only the ‘nuisance’ or trivialities of the diagnosis has a more balanced view of what was ahead of Sally, or perhaps she had limited knowledge of advancing dementia and could not foresee some of the difficulties ahead. Whichever of these rambling thoughts were true, it seemed clear that, as nurses, we would each care for this patient differently, as our differing views of dementia coloured our approach to the patient. The impetus for this study, therefore, emerged from the experiences of Sally and her family and from my own experiences and feelings as a nurse caring for them. I felt that I had to understand more about the nurses’ celebrations and more about what they thought was ahead of Sally and her family.

1.2 Context for the Study

People with dementia are cared for throughout the health service. They use almost every service and can be found in a huge variety of practice settings. Caring for people with dementia is, therefore, the business of almost every nurse. As such, information about the way in which nurses perceive and understand dementia has the potential to inform practice throughout the healthcare industry. Furthermore, this study takes place against the context of an ageing society in which numbers of people living with dementia are set to increase in the coming decades (Alzheimer’s Society 2008). Writing in the early 1980s, Thomas described dementia as a time bomb which is set to explode as the twenty first century continues (Thomas 1983). His words already show signs of coming true as major dementia charity, Alzheimer’s Society, predicts that the number of sufferers is set to increase from 700,000 people in 2008 to over a million in 2025 and 1.7 million by 2051 (Alzheimer's Society

2008). As many as two thirds of these individuals live at home and are supported by family, community healthcare teams and a wide range of day hospital and voluntary sector day care services (Alzheimer's Society 2008). Those admitted to hospital are often admitted to acute areas with infections, broken bones, falls or when the situation at home breaks down. Some are admitted for periods of respite care before returning to their own homes. A number of dementia sufferers are cared for in long term care settings including nursing homes and NHS hospitals. Nurses meet patients with dementia in each of these many care settings and their ideas about dementia and the care of people with dementia are, therefore, hugely significant.

1.3 Research Questions

This thesis seeks to explore how nurses conceptualise dementia and to examine factors which influence this understanding. Through this exploration, the study aims to understand how nurses conceptualise dementia and how this might relate to their practice. The two research questions below were developed in response to experiences from my own nursing practice and, specifically, from my experience of caring for Sally and her family.

- How do nurses conceptualise dementia?
- How does this conceptualisation relate to care and care planning?

1.4 Study Approach and Reflexivity

This study uses a reflexive sociological approach which is based on the writings of French scholar Pierre Bourdieu. The approach, outlined in detail in chapter three, allows factors which influence the nurses' understandings of dementia to be included in the analysis as part of the data. For example, the constraints of NHS hospital settings, relationships with other members of the healthcare team, educational preparation of nurses and previous personal experiences are only a few of the factors

which might shape a nurse's view of dementia and how a patient with dementia should be cared for. In exploring something as nebulous as conceptualisation, it is helpful to be able to analyse fully the social context of the data as well as the individual accounts from nurses.

Bourdieu's approach also requires the researcher to demonstrate reflexivity in all aspects of the study. As a nurse, a researcher and somebody with a personal interest in dementia, reflexivity is an important aspect of my work. I do not come to this study as an artist would to a blank canvas but, rather, bring with me a number of different experiences and ideas which must be made explicit if this study is to be a credible piece of work. Reflection will, therefore, be a key part of this thesis. This will extend throughout the thesis from a personal account of dementia in chapter two to my own reflections on the data presented in chapters five to eight and, finally, an analysis of my own position following the discussion in chapter nine.

1.5 Organisation of the Thesis

Following this introduction, chapter two presents the reader with literature which provides a backdrop to this study. The literature review focuses on two areas. Firstly, literature on the process of conceptualisation is presented. This considers the process of conceptualisation and factors which may influence the formation of ideas. Secondly, literature on dementia covering material from a variety of different schools of thought and outlining ways of thinking about dementia and caring for patients with dementia is presented. This material is critically discussed and its relevance to this study is indicated. Personal views of dementia, including my own, are included in this review.

Chapter three outlines the work of Pierre Bourdieu. The *Theory of Practice* is outlined and its utility in nursing research is discussed. The application of Bourdieu's

theories to this study is then described and diagrams are presented in order to clarify the complex relationships which are key to the data analysis process. Chapter four describes the conduct of the study. The methods used are discussed and many of the pragmatic aspects of the research are outlined. Some of the challenges of designing research using Bourdieu's writing as a theoretical underpinning are also discussed.

The next four chapters present data about the nurses' conceptualisations of dementia. Each chapter shows a different way of understanding dementia and demonstrates how this can be related to nursing practice. Data in each chapter are supported by the inclusion of literature related to the specific topics discussed. By presenting relevant literature alongside the data, I hope to make the thesis more readable and fuse together the academic context of the discussion with views from practice. The first of the data chapters explores the conceptualisation of dementia as a disease. This conceptualisation reflects the dominance of the medical model of care in the field and is an understanding shared by a large number of the contributing nurses. For many nurses this is one of the first conceptualisations that they use to understand dementia and, therefore, this data is introduced early in the thesis. Thereafter, chapters explore the conceptualisation of dementia in terms of memory and confusion. Finally, chapter eight explores the conceptualisation of dementia as a journey. This chapter is the final data chapter, allowing the reader to reflect both on previous data and the range of conceptualisations used by nurses,

Chapter nine brings the data together, considering the four dominant conceptualisations and factors which influence them. These are then related to the wider field of inpatient dementia care. Comparisons between settings are included in this chapter. Chapter ten offers discussion of the nurses' four conceptualisations and factors which influence them. Bourdieu's Theory of Practice is, again, employed to shape reflection on the nurses' motivations and the links that they themselves make between conceptualisation and practice. These discussions serve to explore the main points emerging from the data in order to develop meaningful conclusions. My own

reflections on the data are also included in this chapter. Finally, this chapter presents conclusions and the implications of those conclusions for practice and further research. These conclusions and reflections on the conclusions are set within political and social contexts and the unique contribution of this study in bringing together nurses' ideas about dementia and the relationship between these ideas and practice will be highlighted.

CHAPTER TWO

A SELECTIVE REVIEW OF LITERATURE AND PERSONAL ACCOUNTS

2.1 Introduction

This chapter provides academic context for the study which follows through a selective review of relevant literature and personal accounts. This study considers how nurses conceptualise dementia and how these conceptualisations relate to their care and care planning. In view of this research focus, the literature review begins by exploring the literature surrounding concept clarification and concept analysis in nursing, before considering the process of conceptualisation and its relevance for this research study. Nursing education is discussed briefly and some personal reflections on conceptualisation are offered. Thereafter, this chapter focuses on dementia and introduces a number of different ways of thinking about dementia. Starting with a glance backwards into history, the chapter moves through medical and social models of dementia, discussing some dominant themes in the care of people who have dementia. In a move away from the format of a traditional literature review, the chapter then moves on to explore views of dementia from outwith the field of academic literature. This section focuses on portrayals of dementia available to the general public through books, websites and television. The personal accounts of Terry Pratchett and John Suchet are considered alongside my own personal account of my experiences with my grandmother. A reflective account of my own position as granddaughter, nurse and researcher is offered. Finally, by way of conclusion, the relevance of the literature and the range of sources explored are indicated and the utility of the material in providing context for this research study is discussed.

2.1.1 Search Strategy

Sources for this literature review were identified using CINAHL, Medline, PubMed and Family Studies Abstracts databases. Dementia was included as a keyword accompanied by concept, conceptualise, perception, understanding, disease, social, social construction, memory, person centred, family centred and history. In addition, sources collected during a previous review of literature in 2002 were revisited. Popular literature, television, radio and online sources were identified in a less systematic fashion and are included in order to explore sources available to the general public.

2.2 Clarifying Concepts in Nursing

The research questions for this study emerged from nursing practice and became a real ‘burning issue’, just awaiting the attention of a novice researcher! To my horror, early literature searches found a paper by John Paley entitled ‘How not to clarify concepts in nursing’ (Paley 1996). This was not so much a ‘how to ...’ guide but rather the opposite and pointed out a number of pitfalls in researching concepts for clarification. This find was followed, at a later stage, by an editorial in the Journal of Advanced Nursing by Sally Thorne which she called ‘Conceptualizing in nursing: what's the point?’ (Thorne 2005). These two papers question the very premise of the study which is presented in this thesis and are, therefore, worthy of immediate attention.

Paley (1996) reviews a number of earlier papers which claim to clarify concepts in nursing. He notes that these papers seek to clarify concepts for three main reasons; firstly, in order to build theory through a thorough understanding of the concepts; secondly, to operationalize the concept or thirdly, to improve practice through greater understanding of a concept. The research reported in this thesis explores nurses’ conceptualisation, examining the ways in which they understand and develop ideas about dementia. The impetus for this study came from practice and the intended

benefits of this study are in terms of practice development, with the aim of improving care through a greater understanding of the ways in which nurses conceptualise dementia. In Paley's terms this study falls into his third category – 'improving practice through greater understanding of a concept'. Paley questions whether clarity can ever be reached. Indeed, he suggests that concepts are, by their nature, contested and ambiguous (Paley 1996). Paley's assertions can be contrasted with the positivist definitions of concepts and concept analysis offered by Penrod and Hupcey (2005);

"Concepts are empirically based abstractions of reality or truth ... our purpose for concept analysis is to produce evidence that reveals scholars' best estimate to 'probable truth' in the scientific literature concept analysis is an essential prerequisite to concept advancement (Penrod & Hupcey 2005 pp404-5)."

The work of French scholar Pierre Bourdieu provides a theoretical framework for this thesis. His work is discussed in detail in chapter three. However, Paley's suggestion that concepts are ambiguous fits well with Bourdieu's sociological approach in which different experiences, environments and social hierarchies significantly alter understandings. The contention that the clarification of concepts in nursing should not assume the concept to have one single meaning sits comfortably with the sociological approach shaping this study.

Another issue raised by Paley is the relationship between concepts and theory. The suggestion that theories can be developed from clarified concepts (Chinn & Kramer 1991; Watson 1991) is rejected by Paley, who asserts that theory comes first, determining the meaning of words, objects and actions. This view is in keeping with the views of Bourdieu and other scholars, from a variety of backgrounds, who consider meaning, language and world view to be determined by theoretical standpoint (Bourdieu 1998; Feyerabend 1993; Kuhn 1996). Having considered these points from Paley's paper, I find myself reassured that the theoretical approach

employed in this study prevents even a novice researcher from falling into the pitfalls outlined by Paley. However, Thorne's question about the point of conceptualisation in nursing remains to be answered.

Thorne's (2005) editorial recognises the importance of conceptualisation and analysis of conceptualisation in "non-applied academic disciplines" but questions the benefit of such research in nursing specifically. While she admits that benefit may result from thinking about concepts in different ways, she warns against assuming that these intellectual endeavours result in any tangible benefit for patient care. She stresses;

"The 'stuff' of nursing, however, always must be grounded in our service mandate. The mental representations we create through our conceptual work become the tools that nurses draw upon in the delicate dynamic of applying the general to the particular: that is, selecting from an infinite set of ideas and facts those that illuminate and explain a phenomenon in the unique and local conditions in which nurses interact with patients.

So, conceptualising is a crucial activity but only – I argue – when it has the purpose of enhancing knowledge for practice (Thorne 2005 p107)."

The study presented in this thesis aims to satisfy the purpose that Thorne outlines but, only with the benefit of hindsight, will its utility in this regard be understood. While understanding some of what nurses think and understand about dementia will, on its own, not change practice, it could be anticipated that this greater understanding might influence nurse education and practice in the future. Furthermore, it may not always be possible to press theoretical knowledge into immediate practical use but these understandings may help to build a body of material which does, in turn, shape future research and practice developments in directions as yet not foreseen. Thorne's

remarks remained with me as I started this research project and will be addressed again in the concluding chapter of this thesis.

This chapter now moves on to discuss previous studies of conceptualisation from a variety of different fields.

2.3 Conceptualisation

Conceptualisation is an active endeavour, whereby an individual forms an idea about a particular concept. Some of this process is deliberate, while other aspects of the process are implicit, drawing on previous experiences, learning, expectations and images. The formation of an initial perception of a subject or event is the initial stage in conceptualisation and is, in itself, a dynamic process (Asch 1946). Thereafter, individuals interact with symbols and use cultural and experiential backgrounds in order to make sense of the social world around them and to form personal understandings (Blumer 1969; Meltzer et al. 1975).

Within nursing, the importance of conceptualisation is recognised by Carper in her groundbreaking paper about knowledge. She argues that it is only through understanding the way that subjects are conceptualised that it becomes possible to determine the specific kind of knowledge which is appropriate in the field (Carper 1978). For example, the conceptualisation of health has changed over time from the view of health as absence of disease to a more dynamic view of health which incorporates variations in time and circumstance and includes psychosocial aspects of health. This conceptualisation change has implications for research, education and nursing practice.

Nurses' conceptualisation of illness, individual disease processes and approaches to care are significant in shaping the interaction of nurse and patient. While many studies are theoretical in their approach, the potential of conceptualisation research to inform practice and education is clear. A recent study exploring the conceptualisation of health considers traditional understandings of health and advocates the adoption of an innovative 'capability approach' in meeting the needs of patients (Law & Widdows 2008). Other studies reviewed take a variety of approaches to explore the ways in which topics are understood and how these understandings relate to practice. The topics examined are complex and could be interpreted in a number of different ways; for example, poverty, spirituality and recognition in child support (Houston & Dolan 2008; Pesut et al. 2008; Skevington 2009). Each paper explores different perspectives using theories and practical examples to clarify the various meanings inherent in the concepts under discussion. Clare et al. (2008) use a grounded theory approach to explore data on awareness in people living with severe dementia in long term care. Through analysis of conversations with eighty individuals, the study demonstrates that individuals with severe dementia can retain awareness in relation to self, relationships and environment. Unawareness was also noted in relation to functional ability and ascribing meaning to a situation. This detailed exploration of the topic provides theoretical understandings about the concept of awareness which can be used to shape practice and education in the future (Clare et al. 2008). Conceptualisation research may also be used in order to develop policy in research planning, where multiple understandings are explored prior to decisions being made (Brown et al. 2008; Magnusson 2008).

Conceptualising is important in shaping the way that nurses understand their patients and the diseases with which they live. The way that nurses think about patients influences their interaction and the way in which they plan care. Kitwood also links the way that health professionals view their patients with the manner in which they care;

“Many nurses, social workers, speech therapists, occupational therapists and others who work closely with dementia sufferers seem to operate with a kind of ‘doublethink’. The ‘standard paradigm’ is what they officially believe, on the basis of what they have read or been taught. But also they hold, unofficially and intuitively, a more optimistic and less deterministic theory about dementia; usually they cannot articulate it clearly, but it is this that informs their practice. In a sense even the evidence from medical science is on their side, because some 70% of the variance between neuropathology and dementia is not accounted for (Kitwood 1990 p179-80).”

Kitwood suggests that nurses, and other health professionals, combine different ways of thinking about dementia and use this combined conceptualisation of dementia in their care. This conceptualisation which Kitwood suggests can not be articulated clearly, is influential in shaping nurse-patient relationships in this area of nursing care and is, therefore, worthy of study through the research reported in this thesis. Sabat also emphasises the importance of the ways that carers think, in shaping interaction with people who have dementia;

“Additional, but no less important, decisions involve the ways in which the afflicted is approached and treated at various stages in the progression of the disease: is his or her personhood recognized and supported, or neglected in favour of the assumption that it barely, if at all, exists? Do we treat the afflicted as a 'semiotic subject' – one whose behaviour is driven by the meaning of situations and the ways in which he or she is treated by others – or as one whose behaviour is deemed incompetent and is simply the outcome of a disease process? Do we assume that the afflicted rarely if ever recognizes the need for company, for stimulation, for the same sort of treatment he or she would seek and be given as a matter of course in earlier healthier days? (Sabat 1998 p35)”

Sabat questions assumptions made by those who care for people who have dementia. His questions emphasise the need for healthcare professionals to treat people with dementia as individuals who have personal needs and wishes. Sabat’s rhetorical

questions underline the assertion that the way nurses think about their patients is hugely significant in shaping the outcome of their interactions.

Conceptualisation is a complex and dynamic process which is important in determining knowledge about a specific subject. Research which explores conceptualisation has been carried out in a number of subject areas. These studies explore a variety of theories and perspectives in order to develop understanding about a concept. These understandings may be influential in shaping research or policy or in shaping interaction within a nurse-patient relationship.

Having considered the clarification of concepts in nursing and some previous conceptualisation research, this chapter now considers different ways of understanding dementia.

2.4 Review of Dementia: Voyage of Discovery

“The real voyage of discovery consists not in seeking new landscapes
but in having new eyes”

Marcel Proust (1871 - 1922)

Those who read this thesis come to it with their own view and understanding of dementia. In many cases, these understandings are not made explicit but, rather, form part of the personal view that we each have of the world. For those of us who have had relatives with dementia, or who have cared for individuals with dementia, experiences, faces, expressions and memories might contribute to the picture that we have in our mind’s eye of dementia. Those who read this thesis may also have

knowledge of the wide ranging academic literature surrounding dementia. This review of literature and personal accounts takes the reader on a ‘voyage of discovery’, introducing a variety of ways of thinking about dementia and challenging the reader to look at the material ‘with new eyes’, in order to consider both the material and our own personal positions afresh.

Dementia is an umbrella term used to describe the symptoms and features of a number of different diseases affecting the brain and cognitive function. The most common type of dementia is Alzheimer’s disease but a large number of other causes can be recognised. These may be metabolic, intracranial, iatrogenic or infective and include vascular events, Korsakoff’s, Pick’s disease, thyroid dysfunction, syphilis and tumours, amongst many others. This thesis explores the concept of dementia generally and does not focus on any one specific diagnosis. Dementia increases in prevalence with age and, therefore, the focus of this work is dementia in older people. The following sections discuss some of the different ways of understanding dementia, starting with a glance back to the past.

2.5 Conceptualisations of Dementia from the Past

“To understand the evolution of the concept of dementia it is essential that its history is traced from at least the seventeenth century (Berrios 1987 p829).”

Cognitive decline in older people has been recognised throughout history and has been conceptualised in a number of ways over the course of centuries. Developing medical knowledge and cultural changes over time have led to considerable variation in the manner in which the conditions, more recently known by the umbrella heading of dementia, have been understood. This section takes a brief look into the past and considers ways in which use of the word ‘dementia’ has developed over the

centuries, as well as charting the ever changing concept of dementia from earliest times to present day treatment and research.

2.5.1 Early History

Around 2000BC the ancient Egyptians recognised that old age could be accompanied by a major memory disorder and, while they believed mental capabilities to be driven by the heart and diaphragm, this appears to be the first recorded reference to the concept of dementia (Boller & Forbes 1998). As early as the seventh century B.C., Pythagorus identified the more specific phenomenon of cognitive decline in older people and designated the ‘senium’, or period over the age of 63 years, as a stage of regression, decay and decline (Berchtold & Cotman 1998). The symptoms may not have been common during this period, as many of the population did not reach advanced age. However, it did become enshrined in some of the legal writings of the time. Solon, a Greek judge, revised the legal framework for inheritance, explicitly noting the potential effects that old age could have in impairing judgement (Berchtold & Cotman 1998; Boller & Forbes 1998). This was the first reference to cognitive decline in older people as a determinant of competence or capacity and laid the foundations for many of the debates still prevalent in the field today.

It is unclear whether cognitive decline in older people was understood by Greco-Roman physicians to be a disease or part of the normal process of ageing. Hippocrates did not include any reference to it in his classification of mental disorders, despite recognising the phenomenon. It has been suggested that this may mean that he considered it a routine part of the ageing process, rather than a disorder in its own right (Torack 1983). Hippocrates’ understanding of paranoia incorporated a decline of mental capacity associated with old age, an organic aetiology and a fatal prognosis (Berchtold & Cotman 1998). This could be interpreted as a very forward thinking conceptualisation of what is now known as dementia and the first attempt to explain the symptoms in terms of organic brain damage. However, if this

interpretation is accurate, Hippocrates would have held an exceptional view. Plato and Aristotle both wrote of cognitive decline in the elderly as an expected part of growing old and it, therefore, appears to have been conceptualised as part of the normal process of ageing for many centuries. The study of cognitive decline in older people seemed to be largely ignored between the late Greco-Roman period and the sixteenth century. Empirical research was frowned upon by the powerful religious leaders of the time and little progress was made in the field of medicine generally, as theological doctrine and the authority of the Church went unchallenged (Berchtold & Cotman 1998).

2.5.2 Sixteenth To Eighteenth Centuries

The sixteenth and early seventeenth centuries became a time of preoccupation with mental disorders, their diagnosis and cause. Little knowledge existed at that time about the potential cause of mental disorders and the presence or absence of fever became a defining feature (Barrough 1601). The brain became the focus of study and Barrough went on to describe physical problems in the brain and make connections between those physical changes and the symptoms of mental frailty. These developments in thinking led, during the seventeenth century, to the conceptualisation of the broad term ‘dementia’ as a condition with a variety of causes or branches. Willis, writing in 1684, drew distinctions between the cognitive impairment with which individuals are born and the development of similar impairments during an otherwise healthy lifetime. He noted causes to be ‘errors of living’ such as drunkenness, use of opiates, falls from great height, as well as disease related processes such as epilepsy, palsy and ‘cruel diseases of the head’ (Willis 1684, cited in Berrios 1987 p831). Willis’ attempt to determine the various causes of dementing illness is clearly relevant today. Many of the causes outlined are now more fully understood and some have been established as distinct conditions or processes in their own right. The apparent confusion between intellectual disability and dementing illness has been the subject of some discussion in the literature and has been seen as a rather naïve misunderstanding (Mahendra 1987). However, considered in the context of the limited knowledge of the time, the use of a single

term to cover all cognitive impairments makes a great deal of sense, especially as the available clinical treatment would be similarly minimal in all cases (Berrios 1987).

The attempt to correlate brain anatomy and mental disorder continued throughout this period. Some notable discoveries were made during this period. The dilation of ventricles in the brain was noted during the late 1700s and this is likely to be representative of the atrophy which was later to be associated with dementing illness (Berchtold & Cotman 1998). These conceptualisations seek to explain the cognitive impairments of dementia with direct reference to neuro-anatomy. Social and interactional aspects of dementia are not recognised in the formal medical texts of the time but this would have been somewhat unusual. However, these aspects are also rarely touched upon in popular literature and art of the time. The medical conceptualisation of dementia changed markedly between Greco-Roman times and the beginning of the nineteenth century, as medical thinking changed and knowledge developed. The focus on cognitive aspects of the condition and on anatomical pathology, however, remained constant. The nineteenth and twentieth centuries built on this legacy, inspiring huge developments that have shaped the conceptualisations of today.

2.5.3 Recent History

French physician Phillippe Pinel (1745-1826) introduced the study of people with mental health disorders through his opening of an asylum and his rejection of incarceration as a means of containing those with mental frailty. This development allowed studies to be carried out. Brains weighed at autopsy were recognised to have lost weight. This was later recognised as atrophy and was related to chronic alcohol use or syphilis. Thereafter, links were also made between these features and other dementing processes. The study of brain pathology and vasculature developed, with stroke and atheroma becoming recognisable as precursors to symptoms of dementia (Berchtold & Cotman 1998). Alois Alzheimer first described the plaques and tangles

which were to become Alzheimer's disease in his writing of 1907. He described his patient 'Auguste D', who had been admitted to the Frankfurt asylum in 1901 suffering from memory impairment, hallucinations, poor comprehension and aphasia. Alzheimer examined her brain after her death in 1906 at the age of 51 years, reporting his findings in a lecture which was published the following year (Maurer et al. 1997). His recognition of plaques and tangles in the brain was not, in itself, unique but coupled with Auguste's young age and her symptoms, Alzheimer's account made an interesting case. Alzheimer himself did not claim to have described a new disease but Emil Kraepelin, esteemed psychiatrist of the time, used the name 'Alzheimer's disease' in his psychiatric handbook of 1910, enshrining Alzheimer's name in the history books (Berrios 2004). Research has gathered pace over the hundred years since Alzheimer's disease was recognised. New ways of thinking about dementing illnesses, causes, treatments and genetics have all been explored, along with significant developments in sociological thinking, care strategies and person-centred approaches. The historical development of dementia as a concept has paved the way for current thinking and provides a useful backdrop to the variety of ways of thinking about dementia, which are presented in the pages which follow.

2.6 General Medical and Psychiatric Approaches to Dementia

This section considers aspects of the general medical and psychiatric approaches to dementia. The neuropathology of Alzheimer's disease and other common forms of dementia are outlined briefly. Issues of diagnosis, treatment and prognosis are discussed. None of these topics are reviewed exhaustively, as the purpose of this chapter is to provide context for the reader, highlighting key themes in the literature which will provide a backdrop to the study which follows.

2.6.1 Neuropathology and Brain Chemistry

The neuropathology and brain chemistry of dementing illness are the subject of numerous text books (Dawbarn & Allen 2001; Kerwin et al. 1991; Kerwin et al.

1993; Rogers & McClelland 2004; Stahl et al. 1987; Weiner 1991). For the purposes of research in the social sciences there is a limit to how much information is required in order to make sense of the clinical picture of dementia and its effects on individuals, their families and staff working with them. This section offers merely an overview of what is happening inside the brain of an individual with dementia, describing the anatomical and chemical changes which give individuals the features with which they live.

The neuropathology of Alzheimer's disease, first described by Alzheimer in 1907, is one of its most significant features. Generalized atrophy afflicts all areas of the brain but tends to focus initially on the temporal lobes, hippocampus and amygdala. These changes can be seen with the naked eye at autopsy or, during life, through neuroimaging. Scans are usually only performed in individuals who present with symptoms (Forstl & Kurz 1999) but, in some individuals with a positive family history of hereditary dementing illness who undergo early scans, some of the anatomical changes are also visible prior to the onset of symptoms (Fox et al. 1996; Hulette et al. 1998). This finding, along with the correlation between age and dementia, has led to a conceptualisation of dementia as an inevitable part of ageing which may be triggered earlier in certain individuals and would come to everyone in the fullness of time (Berg 1985).

The microscopic neuropathology of Alzheimer's type dementia includes a number of other factors such as; argyrophilic plaques, neurofibrillary tangles, neuron loss, neurophil threads, granulovacuolar degeneration and amyloid angiopathy. These aspects can only be examined using a variety of stains and microscopy techniques. Plaques and tangles in the brain render the affected areas ineffective and, therefore, correlate with the symptoms and deficits experienced by the individual. In other types of dementia it is possible to chart alternative neuropathological changes. Lewy body dementia, the second most common cause of neurodegenerative dementia (Ballard 2004), is accompanied by a build up of lewy bodies in the substantia nigra

and neuron loss, in addition to the pathology of Alzheimer's disease. Frontal lobe dementias such as frontotemporal dementia are not accompanied by many of the features of Alzheimer's type dementia but rather have an indicative spongy change in the frontal and anterior temporal lobes and filamentous inclusions in the neurons (Dawbarn & Allen 2001). Pick's disease also changes the frontal and temporal regions of the brain, bringing with it significant changes in personality and disinhibition, along with the formation of Pick bodies in the frontal lobe.

Significant chemical changes in the brains of people who live with dementia are the focus of much research attention in a quest to find drug treatments. Acetylcholine synthesis is dramatically reduced which leads to a decline in neurotransmission. A number of proteins have an important role to play in Alzheimer's type dementia. These are β -amyloid and tau which contribute to the build up of plaques and neurofibrillary tangles. The chemistry of these complex syntheses is well beyond the scope of this review and, indeed, my own understanding of neurochemistry. However, in recent years Professor Claude Wischik and his team at the University of Aberdeen, among others, have developed neurochemistry in this direction, exploring the potential development of drugs targeting tau protein and early stage development of plaques and tangles (Wischik et al. 2001).

For the purposes of background to the research which follows, the most important aspects of the neuropathology and chemistry of dementing illness relate to the interaction of this knowledge with the individuals who live with dementia and those who care for them. The following sections discuss diagnosis, treatment and prognosis, bringing together aspects of brain pathology and human interaction.

2.6.2 Diagnosis, Treatment and Prognosis

The SIGN guidelines (Scottish Intercollegiate Guidelines Network 2006) provide a framework for making a diagnosis of dementia and guide physicians, psychiatrists and nurses treating those who have dementia of any sort. Early diagnosis of dementia is now recognised as good practice (Department of Health 2001). The role of making a diagnosis is both clinically and emotionally challenging (Bourdieu 1983; Homer et al. 1988; Rasler et al. 2004; Small et al. 1997). The job often falls to primary care physicians (Fortinsky et al. 1995; Iliffe et al. 2002) or can be carried out by geriatricians or psychiatrists (Rice et al. 1997). Each of these professional groups approaches the subject of diagnosis disclosure differently. For example, general practitioners have been found to divulge different amounts and types of information about the diagnosis to individuals and family members. Some report using euphemistic language and withholding medical facts in their interactions with individuals affected by dementia (Downs et al. 2002), while others withhold the diagnosis or are less than truthful in their disclosures (Vassilas & Donaldson 1999; Vassilas & Donaldson 1998). These findings are particularly significant, as primary care physicians play such an important role as gatekeepers to specialist medical and social services and are an important point of contact for individuals and their families (Downs et al. 2006a; Iliffe et al. 2002). The individual's previous reaction to noticeable cognitive decline is thought to be an important factor in determining their reaction to diagnosis (Ahujn & Williams 2000) and this may play a part in decisions about disclosure. Recent academic interest in mild cognitive impairment also raises the issue of impaired insight, with many patients who attend memory clinic consultations denying any deficits (Comijs et al. 2004; Vogel et al. 2004). These denials may make the disclosure of a diagnosis of dementia all the more difficult for the physician or psychiatrist involved.

Early diagnosis is beneficial in order to maximise both the treatment options available and for individuals to use their time as they choose. The use of medication to help those with early and moderate stage Alzheimer's disease has been controversial, with debates raging in the media and medical journals (Dyer 2007;

O'Brien 2006). The debates centre on the disputed effectiveness of the medications which are designed to improve symptoms rather than offer a cure (Broich 2007; Burns et al. 2006; Dekkers & Rikkert 2007; Voelker 2008). The cost implications of giving medication which has limited efficacy, the practical and staffing demands of ensuring medication compliance in this group of patients and inequalities in prescription and uptake, raise questions about the provision of these drugs (Johnell et al. 2008; Werner et al. 2002). Furthermore, side effects may also cause difficulties in a group of patients who are commonly taking many other prescription medications (Ellul et al. 2007; Gallini et al. 2007). The drug treatments are far from ideal but do offer benefits for some individuals (Lyle et al. 2008). Some family members report significant improvements in cognition and resulting function. These improvements are hugely important to the individuals and families concerned and lead to emotive calls for the medications to be made more widely available. Some Canadian researchers have called for more qualitative research studies to describe the specific treatment effects more clearly and develop realistic expectations for drug treatments in dementia care (Rockwood & Joffres 2002).

Non-drug therapies for dementia also offer significant symptomatic benefits. Art and music (Choi et al. 2009; Cummings et al. 2008; Raglio et al. 2008; Van der Geer et al. 2009; Witzke et al. 2008), movement, reminiscence and behavioural therapies (Flint 2006; Heathcote 2007), memory training and many more have recognisable benefits for individuals (Graesel et al. 2003). These treatments are increasingly being recognised as effective and studies are emerging which demonstrate this to medical and psychiatric professionals and the wider world.

Early diagnosis may have benefits for the commencement of treatment but also allows the individual and his/her family time to plan for the future and opportunity to spend time in the ways that they choose. Prognosis is an important aspect of planning, both at an individual level and also for health service planners (Aguero-Torres et al. 1998; Jagger et al. 2000). Prognosis is notoriously difficult to predict.

Aguero-Torres et al. (1998) followed patients over seven years and concluded that the following factors were predictive of shorter survival with dementia; older age, co-morbidity, impaired functioning, severity of dementia (Schaufele et al. 2002), less education, being male. Different dementia types produced similar lengths of survival although the specific prognostic factors did vary between diagnosis (Aguero-Torres et al. 1998; Parashos et al. 2002). Functional abilities were significant in Aguero-Torres et al.'s (1998) study as prognostic of shortened survival, but function is often used as a gauge of the severity of dementia or to measure the success of care (Wu et al. 2000). Juva et al. (1994), however, noted that severity of dementia and increasing age did not correlate with functional decline (Juva et al. 1994). The study found that declining function did not pre-dispose the individuals to institutionalization although the small sample size makes generalization unreliable.

This section has selectively reviewed literature about medical and psychiatric approaches to dementia. The brief outline of neuropathology and brain chemistry provided the backdrop to the discussions of diagnosis, treatment and prognosis which followed. The material presented is indicative of a larger body of research which explores each of the topics outlined in greater detail. For the purposes of this thesis, the material presented provides context for the data which will be explored in the following chapters. The following section explores research about the social construction of dementia and introduces a different way of understanding dementing illness and its effects on individuals and their families.

2.7 Social Construction and Social Models of Dementia

Human identities are constructed through interaction with people and symbols in the social world. It is on this premise that social constructionism is based (Golander & Raz 1996). The last fifteen years has seen the development of a body of literature dealing specifically with social construction and other social, anthropological and philosophical constructions of dementia (Davis 2004; Poveda 2003). This body of

literature concentrates predominantly on the ‘self’ and ‘personhood’ of the individual living with dementia as, in a social constructionist framework, the ‘self’ is central to the making of meaning and interaction with the social world.

The rise of social constructionism over recent decades can be attributed to a variety of changes in society. For example, as respect for the traditional professions has declined, it has become more acceptable to question dominant medical explanations. Post modernism emphasises the dispersal of power to individuals and encourages individuals to develop through interaction with the wider world and through the presentation of personal narratives (McColgan et al. 2000). These changes in society have contributed to the rise in social constructionism. However, the medical model remains dominant in healthcare generally and social constructionism has only started to become established in areas where cracks are to be seen in the armour of the dominant medical school. In many areas of society, there is an increased medicalisation (Aho 2008; Bury 2009; Seymour 1999). However, in dementia research, the social constructionists and the social movement which has developed around their school of thought, have become important voices in the literature.

The rise of the new right in world politics during the 1980s and 1990s has left a legacy of individualism in its wake. In this ‘new society’, individuals are increasingly responsible for their own lives, as the role of the state in the daily lives of individuals in society is reduced. Individual responsibility for personal well being has led to a need for people to label failings in a manner that is acceptable within the dominant culture. Without such labels, the ‘blame’ for perceived personal deficiencies would logically fall to the individual. It could be argued, therefore, that the changing role of the state in modern Western society has perpetuated the increased pathologisation of difference within that society (Nolan 1998). Against this backdrop, the medical label is an important part of the individual’s identity, creating a powerful symbol that can become the focus of interaction.

The label also demonstrates the power of the medical school more generally. Personally experienced conditions are not legitimised by wider society until they are given the perceived authority of a medical label and, therefore, the biomedical paradigm pervades all aspects of society (Harding & Palfrey 1997). In a wider context, the medical model represents the importance of causal relationships and the pursuit of truth through scientific enquiry and has become a dominant doctrine in society at large. In the field of dementia research, however, social constructionists are developing powerful arguments to challenge the dominance of biomedical science. The social construction of dementia must, therefore, be explored in greater detail. This section seeks to outline the place of social constructionism in the field of dementia research, highlighting the societal conditions and some of the deficiencies in traditional medical arguments that have allowed social constructionist arguments to emerge. This section also selectively reviews literature on the place of the 'self' in dementia, outlining research in this important area and demonstrating how the person centred care movement has emerged from this research.

2.7.1 Dementia as an 'Impure' Example of Social Construction

Harding and Palfrey (1997) present dementia as a label given to people who develop deficits in memory, by the dominant medical movement. They reject the biomedical explanations for these changes in ability, suggesting instead that it is the manner in which members of society react to these ability changes that has perpetuated the labelling. The purely social constructionist view of Harding and Palfrey is, however, not representative of the literature as a whole and appears to take little account of the most recent advances in biomedical research (Watson 1999).

Other authors have considered ways in which dementing illnesses are constructed socially (Cohen-Mansfield et al. 2000; Golander & Raz 1996; Sabat 1994; Small et al. 1998). However, while the importance of social interaction is emphasised by all of the authors, none disregard neuropathology entirely. For example, Golander and

Raz (1996) suggest that “dementia is dually constituted by psycho-biological pathologies and social processes of labelling (p269).” Similarly, both Cohen-Mansfield et al. (2000) and Small et al. (1998) highlight the importance of cognitive and social factors in the dementing process.

While there is a considerable and growing literature on the social construction of dementia, dementing illnesses may be considered to be only partially socially constructed. The neuropathology of dementia is seldom disregarded in its entirety and is widely acknowledged to be an important contributory factor in the course of dementing illness. That is not to say that the social construction case has not been made. Considerable evidence exists to suggest that much of the behaviour and disability related to dementia, may be socially constructed (Sabat 1994; Vittoria 1999; Wood & Ryan 1991). This evidence will be outlined in more detail in the pages which follow.

2.7.2 Challenges to the Medical Model

Prior to the recent upsurge in social research on dementia, the field was dominated by medical research. Neurobiological factors were explored, brain tissue was examined and medication was used to control and alleviate some of the symptoms of dementing illness that were seen to be undesirable (Golander & Raz 1996). This approach to dementia could be seen to be a very ‘problem centred’ approach, emphasising the negative aspects of the dementing process, rather than the remaining positive features of the individual sufferer’s life.

“I really don’t like to be, uh, talking about what, what’s my trouble. Going always to see people to see what’s wrong with me (...) Few of us desire to have relationships with others in which our shortcomings are constantly the main focus of interaction (Sabat 2002 p30).”

This excerpt from Sabat's conversation with a retired professor, living with dementia, emphasises the perceived negativity of a medical approach to dementia.

A further deficiency in the medical model of dementia results from the lack of clarity of the medical case. The neurobiology of Alzheimer's disease and other dementing conditions was outlined earlier in this chapter. Some of the available medical evidence raises issues (Golander & Raz 1996). For example, some people who have no discernable symptoms of cognitive decline have evidence of neuropathological change at autopsy (Tomlinson et al. 1970) and other scholars have argued that dementia is simply an exaggeration of normal ageing (Berg 1985). These issues contribute to a lack of overall clarity in the medical approach to dementia which leaves space for alternative explanations to be proffered.

Increasingly, research has suggested that neuropathology alone can not account for all the effects and manifestations of dementia (Homer 1988; Kitwood & Bredin 1992; Sabat 1994; Sabat & Harre 1992; Tomlinson et al. 1970). The desire to explain differences in functional capabilities between people with similar degrees of neuropathological damage and, furthermore, to explain fluctuations in an individual's behaviour between care settings or within different caring relationships, have encouraged researchers to look beyond the biomedical and to consider the wider, social and interactional aspects of dementing illness (Lyman 1989; Taft et al. 1997).

2.7.3 Focus on 'The Self'

A great deal of the literature about the social construction of dementia focuses on the place of the self in dementing illness and in our perceptions of dementing illness. Constructions of dementia by society are based on interactions, both with people who have dementia, and with images of dementing illness found in society at large. In both types of interaction the individuality, personality and competence, embodied in

the ‘self’ of a person, are questioned. While the loss of a limb or of one of the senses challenges an individual to make significant changes in their lifestyle and may have important psychological effects, the damage associated with dementing illness presents different challenges. The reasoning abilities, communication and predictive powers, personal preferences and beliefs that help to make each person individual, are eroded by the symptoms of dementing illness. The very essence of being an individual human adult is, therefore, under attack.

If people living with dementia are seen by society as ‘non people’ or people who are missing some of the key features of humanity - namely a sense of self – this may be a key determinant of how society interacts with people who have dementia. The social construction literature, therefore, considers the place of the self in dementia, seeking to determine how far along the illness trajectory aspects of self can be recognised and highlighting ways in which the self can be undermined or maintained through care strategies and practices.

2.7.4 Loss of Self

A book first published in 1986 entitled *‘The Loss of Self’* underlines one common perception of dementia as the cause of a ‘living death’ in which the physical body survives, but the mind and individuality are destroyed (Cohen & Eisendorfer 1986; Cohen & Eisendorfer 2002). The book is intended as a resource for families affected by dementia and includes input from those living with dementia, informal carers and professionals. It is a helpful and positive resource, offering suggestions about ways in which life can be made easier and more fulfilling for both the person with dementia and his/her family. The title of the book, however, casts a shadow over the text and the positive messages presented.

Individual contributors to ‘The Loss of Self’ present their own feelings about life with dementia. James Thomas suffered from Alzheimer’s disease and allowed the following two passages from his daily journal to be used in the book;

“I am hungry for the life that is being taken away from me. I am a human being. I still exist. I have a family. I hunger for friendship, happiness, and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for! Help me to be strong and free *until my self no longer exists* (Cohen & Eisendorfer 2002 p21).”

“No theory of medicine can explain what is happening to me. Every few months I sense that another piece of me is missing. My life ... *my self* ... are falling apart. I can only think half thoughts now. Someday I may wake up and not think at all ... not know who I am. Most people expect to die someday, *but who ever expected to lose their self first* (Cohen & Eisendorfer 2002 p21).”

These two passages highlight the importance of losing aspects of the personality that defined the individual and helped him to act autonomously in line with his values and beliefs. The process that the contributor calls ‘losing his self’ and the authors have used as the title of their text, is the process discussed and debated in the social construction literature. In a wide variety of ways this phenomenon is highlighted throughout the dementia literature, specifically, in work by and with people who live with dementing illness (Friedell 2002; Sabat 2002; Sterin 2002). The debate does not centre on the accuracy of the account of this degenerative process as each individual experience is different but, rather, it focuses on the reasons for the perceived erosion of ‘self’ and the factors which contribute to and exacerbate the process overall. The body of literature concentrates particularly on aspects of the process which are perpetuated socially or reinforced through social interaction. The following sections will review some of the literature around the complexity of self, malignant social psychology and practice developments intended to promote the maintenance of self.

2.7.5 The Complex Self

The complexity of the study of self has been considered in psychology literature since the late 1930s. Research has suggested that the human self is not constant but, rather, it depends on the situation, company and needs of the time (Goffman 1971; Stern 1938). Much of the literature about the social construction of dementia focuses on exploring how people living with dementia feel about themselves and their functions (Pearce et al. 2002; Saunders 1998a) and how interactions between people with dementia and society reflect the dementing illness (Saunders 1998b). The diagnosis and reality of dementia may alter the beliefs that an individual has about him/herself. Anger, grief, embarrassment and hopelessness are some common feelings that the individual with dementia experiences (Cohen & Eisendorfer 2002; Sabat et al. 1999; Sabat 2002). However, these combine with previous attributes and beliefs about the self in previous, healthier, times to create a new sense of self which endures into advanced dementia (Dworkin 1986). Conflict may manifest itself in this process as the attributes of the past and present collide in the formation of the new self (Sabat et al. 1999; Sabat 2002). Individual agency also changes as priorities and autonomy are determined by the changed or dementing self (Cohen-Mansfield et al. 2000). However, strong elements of self identities can often be seen in the behaviour of people with dementia. For example, occupational or role identities are often exhibited (Golander & Raz 1996; Sabat et al. 1999).

The representation of role or occupational identities in people with dementia may be related to the individual's projected identity. Sabat et al. (1999) highlight the ability of people living with dementia, to choose interactions that they perceive to demonstrate their skills rather than their deficiencies. Language and stories can also be used by people with dementia to retain or reconstruct identities and to project specific identities to other members of society (Shenk et al. 2002). The projected self can only be promoted in interaction with someone else. It is, therefore, only through interpersonal co-operation that the individual with dementia can project the desired image to the wider community. This interaction will be coloured by the individual's own reaction to the neuropathological changes and resultant cognitive decline,

coping strategies, manners and social behaviours. However, the reaction of the conversant will be crucial to the interaction. The focus on the deficiencies associated with the disease process and reinforcement of negative features of the interaction will contribute to the negative communicative experience of the person with dementia. Similarly, the conversant's interest and focus on positive aspects of the individual's personality and unique story has the potential to boost self worth and reinforce positive aspects of identity.

The complexity of the self as a concept is evident, however, the importance of exploring the place of the self in dementia is clear. Challenges in research of this type are considerable. For example, some studies take place in memory clinics where the inherent power dynamics may influence the interactions recorded. Furthermore, much of the research on the self and dementia focuses on discourse and the use of language. Some people with dementia have declining language function or are unable to initiate appropriate conversation and there are often significant differences in age between care staff and resident which may lead to variations in styles of conversation, particularly around forms of address (Wood & Ryan 1991). Sabat and Harre (1992) analysed the discourse of three people living with dementia. They paid particular attention to the use of indexicals such as 'I', 'me' and 'my' in order to ascertain how intact the individual's sense of self was during the discourse. The use of the first person and of statements which demonstrate reflexivity on the part of the speaker were considered to be important indicators of the maintenance of self. The work of Sabat and Harre (1992) was groundbreaking work but the discourse analysis has been challenged by Small et al. (1998) who considered it important to include other indicators of personal belonging in their own work in this area (Small et al. 1998).

2.7.6 Malignant Social Psychology and the Work of Kitwood

The work of Kitwood is central to the body of literature on dementia care generally and in the area of self and personhood specifically. The publication, in 1990, of a theory of dementia that moved away from the traditional medical focus, was ground breaking (Kitwood 1990). Kitwood's paper presented dementia, for the first time, as an interplay between psychosocial and neurological factors. His research uses vignettes to highlight the importance of psychosocial factors in determining the behaviour of people who are diagnosed with dementia. Kitwood's work also introduced the term '*malignant social psychology*' which he describes in terms of ten aspects of interaction that depersonalise the individual with dementia. These are – treachery, disempowerment, infantilisation, intimidation, labelling, stigmatisation, outpacing, invalidation, banishment and objectification (Kitwood 1990). Kitwood seeks to explain why people who are neurologically impaired 'attract' malignant social psychology from the people interacting with them. He deals very sympathetically with some of the issues raised by the care settings, outlining the multitude of challenges encountered when caring for people with dementing illness and the possible reasons for negative outcomes to emerge from these situations. Kitwood presents malignant social psychology as part of a spiral of decline in the dementing process. The models presented by Kitwood (1990) suggest that as neurological impairment increases, the interactions of individuals with the person who has dementia decrease in quality. This process reinforces the cognitive losses and perpetuates the social impairment of the person, thus further emphasising the cycle of decline. Kitwood's theory of malignant social psychology has serious implications for care of people with dementia (Kitwood 1990; Kitwood & Bredin 1992). These issues will be addressed in the following section.

2.7.7 Excess Disability

The concept of excess disability can be related to Kitwood's theories. Kitwood's suggestion that interactions with dementia sufferers play an integral part in the dementing process, is important in terms of analysing how people react to people

who have dementia. The concept of 'excess disability' was developed by Brody (1971) and is very much related to Kitwood's malignant social psychology, as the term describes the behaviours of people with dementia who are disempowered by the negative interactions of those around them (Brody 1971). This disempowerment creates a situation where individuals are unable to act on their own initiative or maximise their own independence. As a result, excess disability undermines the confidence and functional abilities of the person with dementia, causing isolation, withdrawal and undermining the individual's self esteem (Sabat et al. 1999). Examples of excess disability can be identified throughout the dementia literature with examples of interactions causing increased disability and new functional deficits (Sabat 1994; Sabat & Harre 1992).

2.7.8 Person Centred Care

The person centred care movement in the field of dementia has an important contribution to make (Woods 2001). This movement has been led, in the UK, by Tom Kitwood and his colleagues who recognised 'malignant social psychology' and offered person centred care as a means of alleviating the problems associated with this kind of interaction (Kitwood 1993; Kitwood 1997; Kitwood & Bredin 1992). The importance of interaction in determining the behaviour of people with dementia has been highlighted earlier in this section. Small et al. (1998) found that staff have huge amounts of control over both the positioning of residents in a care setting and also in initiating interactions. This has implications for nurses and carers working with people who have dementia. Jenkins and Price (1996) emphasise the need for nurses to consider more than cognitive and functional abilities in their care of patients and insist that personhood should be an integral part of nursing care of individuals with dementia (Jenkins & Price 1996). Furthermore, social context should be explored in order to develop understanding of the experiences of individuals living with dementia, both in practice (Pratt & Wilkinson 2003) and in research (Downs 1997).

Kitwood's life's work centred around presenting people with dementia as individuals, promoting their independence and caring for their needs appropriately. The literature on the maintenance of self in dementia also highlights the importance of reinforcing personal attributes and biographies. It is recommended that care givers validate the autobiographical memories of individuals in order to reinforce and recreate the self of the person with dementia (Golander & Raz 1996; Mills & Coleman 1994). This can be effective even in those who live with severe dementia (Norberg 1998). The person centred care movement, as outlined by Kitwood, encourages care staff to interact positively with people who have dementia, focussing on strengths and residual abilities rather than deficiencies. This approach allows staff to promote independence and reinforce aspects of individual biography. In recent years, the person centred care approach has been considered too narrow and relationship centred approaches have been developed to incorporate the relationships between family members, carers, professional care staff and those with dementia (Greenwood et al. 2001; Nolan et al. 2001; Nolan et al. 2002; Nolan et al. 2004; Nolan et al. 2006; Nolan et al. 2008). Recent work by Trevor Adams has gone further, explicitly relating social and psychological systems to the relationships (Adams 2008).

Social construction and some of the social approaches to dementia which have developed in recent decades have been presented in this section. While literature has not been exhaustively reviewed, the material presented offers context for the study which will be presented in the remainder of this thesis. Social construction and its socio-political context were introduced. The sense of self, which is key to this body of literature, was outlined and some research in this area discussed. Thereafter, malignant social psychology, the work of Tom Kitwood, and excess disability were presented as some of the difficulties associated with the undermining of the sense of self. Person and relationship centred care were highlighted as approaches to care which are considered beneficial in the field. In the following section ideas about models which explain dementia, discussion of ageing and nursing older people will be presented.

2.7.9 Explanatory models

Having firstly explored historical views, then considered medical and psychiatric views of dementia this chapter has now also outlined social constructions of dementia, providing evidence of a range of constructions of dementia. Different “ways of seeing (p209)” dementia are explored and contrasted by Downs et al (2006b). Their paper primarily contrasts neuro-psychiatric and person-centred approaches to dementia, making briefer mention of normal ageing and purely neurological models. The paper highlights the importance of the explanatory model which is used in shaping the action permitted by the carer or nurse. For example, using the person-centred approach to dementia permits the nurse to contemplate the use of palliative approaches in shaping care strategy. This assertion is explored in more detail in Downs (2006c) where each explanatory model is considered specifically with reference to the ‘therapeutic effort’ which naturally results from the use of that explanatory framework.

2.7.10 Ageing and Nursing Older People

The position of older people in society is the subject of both media attention and academic debate (Bernard & Phillips 2000). This debate has significance in healthcare, as increasingly large numbers of older people receive nursing care. The attitudes of nurses who care for older people, particularly in acute care areas, are often poorly researched with outdated measurement tools (Courtney et al. 2000). However, evidence suggests that ageist attitudes prevail in society at large and in nursing specifically (Bernard 1998; Scott et al. 1998). Tackling ageism through education which focuses on younger people has been shown to have limited effectiveness (Scott et al.1998) but the need to find an effective strategy to address this problem is clear (Koch & Webb 1996). The importance of communication between nurse and older person has been established and programmes have been put in place to improve communication between student nurses and older people, with a view to developing good practice at an early stage (Tuohy 2003). The attitudes to ageing and the care of older people which prevail in society at large may be

influential in shaping nurses' views of dementia and may be useful context for the presentation of the data in this thesis.

This chapter now moves away from the format of a traditional literature review and moves on to consider material which may influence conceptualisation of dementia amongst individuals. Sources such as personal accounts are considered, alongside popular literature, websites and television programmes. My own personal account of dementia is also considered in this section.

2.8 Dementia in Popular Sources and Personal Accounts

A formal academic literature review would rarely include material from popular sources or personal accounts. However, this research project seeks to explore nurses' conceptualisation of dementia and, in order to explore the many different ways of considering dementia that may have influenced the nurses in their thinking, it is necessary to explore sources which fall outwith the normal realms of an academic literature review. Cayton (2004) suggests that stories may be helpful ways of making sense of dementia and, therefore, personal narrative is included in this review. The section starts with my own personal account, reflecting on my grandmother's dementia. Thereafter, some books, television and radio programmes are reviewed before the remarks of John Suchet and Terry Pratchett are discussed. Some concluding remarks highlight points which may be relevant in the research which follows.

2.8.1 Dementia: My Own Personal View

My grandmother suffered from dementia. She followed in the footsteps of other family members who have suffered in similar ways. Throughout my work, I am careful to describe people 'living with' dementia, as many would suggest that the language of affliction paints an unnecessarily dark picture of life after diagnosis.

Many people, it is argued (Bryden 2005), can find fulfilment living positive and busy lives after the diagnosis of dementia. However, Gran did suffer. From the early, embarrassing days of duplicated birthday cards and wrongly baked cakes, to the acute distress of being lost in her own home, I can say with certainty that, at times, she suffered. I make this judgement as a granddaughter, a nurse and a researcher. These roles overlapped and collided as I interacted with my grandmother, her dementia, my previous experiences of dementia and the theoretical understandings that I have of dementing illness. These roles all influence the story that I tell in this brief account.

Family is an important part of my life. As a family, we are close both geographically and emotionally. My grandmother grew up in Edinburgh and had a number of aunts and uncles who had dementia in later life. Her own mother was also afflicted and was looked after for some years by my grandparents within their family home. The legacy of dementia is rather daunting. There is an unspoken fear that it may, in turn, affect my father or, indeed, myself. Although this is not at the forefront of our thinking and is never discussed, these thoughts provide a contextual backdrop for the remarks which follow.

My family experiences of dementia clearly influence my views and feelings about the dementing process. However, my interest predates my grandmother's diagnosis and a professional view must also be considered, particularly as my first interaction with people diagnosed with dementia was in the capacity of student nurse. My first experience of caring for people who have dementia was a practice placement experience at a day care club. This proved to be an influential placement at a club which used imaginative and sometimes unorthodox approaches to care. The staff were clear that the clients should be treated first and foremost as people. The dementia was very much secondary and the staff were skilled in ensuring that interactions were social in nature rather than formally 'therapeutic'. As an inexperienced student, I felt positive about this approach to care. There were aspects

of the approach which could be criticised but my over-riding understanding at the end of the placement was that people with dementia are just that, people first. The club also provoked my interest in how people think about and understand dementia. During reflections at the end of the club day a member of staff talked about one client whom he had trouble working with. He explained that he found work with this client difficult, not because he disliked the individual on a personal level but because he disliked her dementia. The notion of this split between an individual and their dementia is a conundrum which has stayed with me.

With this placement behind me, I became an advocate for the rights of people who have dementia to be treated individually and to have the same opportunities afforded others, particularly in a health care setting. Autonomy and empowerment have, in recent years, become key parts of the new language springing up around dementia care. All too often, they are associated with empty rhetoric and roll off the tongue of service providers without any real consideration of the implementation of either concept. I still feel outrage when I remember a care setting where tables were set at meal times with floral table cloths and co-ordinating napkins and menu cards. I was a visitor in the area and commented on the effort that had been made to make this group of dementia patients feel that this meal time was special. The nurse in charge laughed and spoke in a conspiratorial tone when she told me that it looked great but that you can't really give people with dementia choices, so you just give them the menu and ask if they'd like the chicken, or alternatively, you could bring them the meal and tell them that they had ordered it, as they would be unlikely to remember that no order had been taken. I feel very strongly that people who have dementia can make choices for themselves and should be properly supported by their carers in order to do this within their individual capabilities. For some, that may mean that they can give consent for treatment or research but, for many, it might mean that menu or clothes choices are the extent of their individual autonomy. I believe that they should be allowed that autonomy and then be cared for sensitively when even these limited levels of autonomy are no longer possible.

As a nurse, I have spoken to some people about their dementia and have been present when the diagnosis has been given to others. We have talked about memory problems and strategies which might help to maintain functioning as long as possible. The practical issues involved with 'living with dementia' are often a prime concern for patients and relatives. In my experience, people talk a great deal about declining function and what they might do when they require help with personal care, food preparation or shopping. There is a focus on the functional which seems to over-ride everything else. This focus on function will be raised throughout this thesis and in discussion in chapter nine. The emphasis on the functional and control of symptoms allows nurses and their colleagues to 'tidily' sort out issues and take some control of the muddle of dementia. As a nurse, I know that I have often taken comfort from 'being busy' in this way.

At a personal level, the practical concerns were also dominant. How could we ensure that Gran had hot meals each day, clean clothes to wear and was safe and comfortable within her own home? At times, these arrangements were complicated and required much of the family's energy. However, while the complexity of the mundane became a focus it was easy to forget that the dementia was stealing more than the purely functional. I remember vividly leaving my grandmother's home one day after a visit, with the sudden and terrible realisation that she would never be the same again. With my academic interest in dementia, I am clearly in a better position than most to understand the decline of Alzheimer's type disease. The irrevocable damage should certainly not have come as a surprise but, at times, it did. It became clear that not only was functional capability declining but conversation, camaraderie, personality and firmly held beliefs had changed too. Equally unexpected were the revelations made and opinions shared, after years of being carefully filed away in a part of the brain which should only be accessed in the most private of thoughts. Personal views of family members, opinions on events of thirty years ago, until now never uttered, were shared as if they were idle tea time chit chat. As a relative, these extra insights were strangely thrilling as 'secret' family revelations were uttered. However, these inappropriate snippets, revealed by a brain which was beginning to

leak information either into the darkness of space or in conversation, were not really for our ears and were accompanied by feelings of guilt in those who heard them. These changes may have been small but there was an overall transformation in my grandmother which made her almost unrecognisable at times. On the ward, family members have asked me what will happen when a mother or father no longer recognises them but few have considered how they will feel if that relative suddenly becomes almost unrecognisable to them.

In my own family, like many others, dementia has forced roles to change, as parents require the care of grown up children and caring responsibilities weigh heavily on some family members. The dynamics of these situations are challenging but, within families where dementia is no stranger, they are often repeated from one generation to the next. My grandmother looked after her own mother who lived with dementia and had great difficulty with many aspects of this period in her life. She remembered caring for her mother but did not accept any comparison between her mother's experience and her own. Perhaps this was self preservation or, perhaps, she really could find no similarities between the two experiences. Even as I play with this conundrum on the page, I am aware that the potential of dementia is perhaps so awful to consider, that the brain, at some level, refuses to make connections to previous experiences which might shed light on what is ahead.

While this is a rather speculative discussion, it takes me to another area of my own thinking on dementia. Diagnoses of life threatening or life changing illnesses are given to people with caution and are often accompanied by plans for the future. Diagnoses of dementia in older people are, however, often withheld or given rather arbitrarily by clinical staff. A similar diagnosis in a fifty year old would be accompanied with insights such as treatment options and prognosis. This allows planning and the potential for 'living positively' although it, doubtless, also can lead to depression and despondency about the future. I think myself that people have a right to know and a right not to know. Some will choose to know what might be

ahead, while others would prefer not to have any idea. However, I believe that older people have this right, in the same way as their younger counterparts in the memory clinic waiting room or admissions ward.

My personal and professional understandings have not always sat comfortably together. As a relative, my own emotions and thoughts have undergone changes. Humour in the early days gave way to feelings of poignancy, when skills which were never passed on were lost. Of course, these skills are retrievable to those of us with the resources to search for them. Nevertheless, fleeting moments of regret linger, as one considers the things we never thought to ask. The memories and details of oral history are far less easily retrieved. Indeed, many of the silly passing details that add colour to a life story have been lost forever. Black and white pictures can be put together from family history, documents and the memories of those still able to share them. The colour, however, is lost and the irretrievable nature of its loss is, at times, painful. As a nurse, with adequate knowledge of brain function and pathology, I am well aware of the declines and have understandings of strategies and treatments, not to mention some of the potential hurdles which loom around the next corner. However, this knowledge has, at times, put me on a collision course with other family members and also within myself. I have been required to consider carefully the standards that I hold dear in my professional life and think about how they transfer to my family situation. For example, as a nurse, I would be tempted to adhere to the wishes of a patient who states quite clearly that she does not wish to attend day care as she does not like the club and would much prefer to stay at home in her own company. It is, after all, the individual's right to choose whether or not she attends the service and to decline the input if she so wishes. However, I found myself persuading my grandmother that the day club would be fun and the company good. This raises questions about why my own standards vary so much between the professional and personal spheres.

In part, the focus on the functional answers this particular dilemma. The interaction of the club helped to keep Gran more alert and orientated, while ensuring that she had a hot meal. Furthermore, this service was an important part of keeping her in her own home and was, therefore, worth the sacrifice of her minor request, in favour of the more major request to stay at home. Practical concerns seemed to have overtaken the standards that I would seek to uphold for a patient in my care.

After a number of years of care at home, we were forced to look for residential care for my grandmother. Distress and agitation, combined with total non-recognition of her home, made the situation unsustainable. This was a difficult point to reach and brought each of my own roles into sharp focus. As a nurse, I could consider the options and realise that everything had been done to keep her at home. As a granddaughter, I recognised the extreme distress and increasing desperation of the telephone calls and was fully committed to the move into residential care. While I regret the fact that the move was necessary and am aware that it is not what my Gran wanted for her last years, I feel certain that this was the only move possible. As a daughter, I recognise the burden of responsibility and pain that my father felt about making this decision on his mother's behalf. This is a burden that can not be shared. Despite the wholehearted support of his family, responsibility for my grandmother rested very clearly with my father.

The analytical and questioning skills of the researcher are new to me, both in my academic work and in the personal sphere. The analysis of some of my own thoughts and feelings, presented in this story, has been a challenge to me as a novice researcher. I do not feel that I have a strong personal identity as a researcher and have found it difficult to consider how this identity fits into the story. However, my desire to explore the concept of dementia has driven me into the research area, with both personal and professional experiences of dementia as background. From the field of research, I have developed more questions and now look at both my personal and professional experiences in a different and more analytical way. The researcher

within me has, at times, made me stop and think more carefully about what I see and experience. This has allowed me the opportunity to gain more from my personal experiences and interactions with dementia than might have been possible, without the insight developed from the research.

In conclusion, I should try to sum up how I understand dementia before considering the views of others. As I see it, dementia is, initially, life changing and, ultimately, life threatening. In the early stages, it can be incorporated into a lifestyle and can be disguised by use of individual strategies. Some can 'live positively' with the diagnosis, making the most of capabilities and benefiting from the good times. Others are isolated by the fear of making mistakes, being lost or simply thinking ahead. I have not met anyone who lives well with dementia throughout the course of disease. My personal view is that everyone suffers from their dementia at some point. The lucky ones have long periods of calm and short periods of fear, frustration or agitation. Perhaps they are the 'pleasantly confused', happy and secure in the world in which they live. For others, the agony can be less short lived and the torment of disorientation or agitation are all encompassing. For many, dementia is a journey from one of these phases to the other, sometimes over the course of months and sometimes on many occasions during a single day. In older people, it is relatively rare to see those in the final stages of dementia. The complete inability to communicate, move, feed or swallow is devastating. In my view, it is a living death, only made worse by the remarkable length of time that people can remain in this state. Nobody seeing someone in this state would talk about 'living positively' with dementia. Indeed, it is barely recognisable as the same condition described by those in the early stages. Many diseases change people physically and psychologically. In my view, few are as devastating or all encompassing as dementia.

This account reflects my own personal and professional insights. It was initially written in advance of data collection and has not been altered with respect to the data analysis that is presented in this thesis. Some reflective remarks about my own

personal position will be incorporated into discussion in chapter nine. The following sections draw on sources of popular literature, websites, television programmes and individual accounts. These sources are used, as nurses may draw on similar sources in their own development of ideas about dementia.

2.8.2 Dementia in Popular Sources

Dementia is not only the subject of medical text books but has come to be part of popular literature. Early observations of dementia are made in the writings of Chaucer, Jonathon Swift and in Shakespeare's Hamlet and King Lear. More recently, John Bayley's moving account of his marriage to Iris Murdoch has offered insights into life with dementia. Many people saw Judy Dench's portrayal of Iris on screen and enduring images of dementia were formed. The view that many people have of dementia may come from insights such as these.

Popular literature raises a number of issues about life with dementia, which may be influential in shaping understandings. For example, Linda Grant and Michael Ignatieff both talk of the perceived inevitability of hereditary dementia in their books;

“When I am old and I have the disease my mother has now... (Grant 1998 p40)”

“Memory is the only afterlife I have ever believed in. But the forgetting inside us cannot be stopped. We are programmed to betray. (Ignatieff 1994 p4)”

Linda Grant also comments on the difficulties faced by relatives when a family member changes, information is lost or an individual becomes less recognizable.

“It did not matter to my mother, but it did to me, that with her memory, that vast house, was passing away a whole world which when it was gone would be finally beyond any recall, the life that existed on one summer day in 1950 when she and her husband and brothers – and sisters-in-law sat on the lawn of the garden of my aunt’s house in Leeds.”

“But it was not so much, as the old song went, ‘Mother you hardly know me’ as ‘Mother we hardly know you’.... Or was it that she finally lost those mechanisms of repression, of covering up, of not letting on or giving yourself away, telling other people your business (Grant 1998 pp24-5)”

Much like myself, Linda Grant experienced the discussion of previously withheld information which signified an important change in the individual. Her writing highlights the finality of memories lost and demonstrates the regret that she herself felt about these losses.

Linda Grant also makes interesting remarks about memory;

“Soon she will no longer recognize me, her own daughter, and if her disease progresses as Alzheimer’s does, her muscles will eventually forget to stay closed against the involuntary release of waste products. She will forget to speak and one day even her heart will lose its memory and forget to beat and she will die. Memory, I have come to understand, is everything, it’s life itself. (Grant 1998 p17)”

These remarks can be clearly linked to the views of some of the nurses who contribute to the study reported in this thesis. Grant’s understanding of memory indicates something of her conceptualisation of dementia as a memory problem, an understanding which is dominant in both lay and professional people.

Television is another source of information and influence. In recent months, a number of programmes have dealt with the reality of dementia, with a controversial documentary about death from dementia being aired in 2008 and recent documentaries following Terry Pratchett in the first year since diagnosis. 'Malcolm and Barbara' charted the decline of Malcolm over an extended period of time and culminated in his eventual death. Barbara, his wife and carer, spoke of her frustrations and exhaustion, her time spent with her husband and their wish that he should die at home. This programme showed Malcolm in his final hours and debate raged in the media about the decency of this portrayal. However, the programme did raise the issue that people can die from dementing illness, a fact often overlooked by public and professionals alike.

Terry Pratchett's programmes discuss many aspects of care and treatment for people with dementia. The rare form of Alzheimer's disease from which he suffers is discussed and his own journey through a variety of alternative treatments makes interesting and, at times, humorous television. However, during filming and in BBC radio interviews, Pratchett has made a number of interesting and insightful remarks about his view of dementia prior to diagnosis, and now, in the time post diagnosis. Previously, he considered dementia to be a disease of old people, a commonly held view which he is now keen to dispel. He also stresses that he does not want to be defined by his diagnosis. With many bestselling novels and thousands of adoring fans, it seems ridiculous to expect that dementia would be his key defining feature. However, web references and media introductions now often define him in that way. Finally, Pratchett remarked in a recent radio programme that he would 'like to believe there's a common experience' of dementia. This remark, and his desire to seek out others who live with dementia, is interesting in that many aspects of dementia are individually experienced and, yet, he considers a common understanding of dementia to be positive.

Finally, John Suchet's recent emotional remarks about his wife's dementia demonstrate the personal cost and frustration of dementia;

"It's devastating ... an awful awful disease. Day by day I'm losing Bonnie. Already the Bonnie that I knew and loved have gone but she's physically still there. How do you cope with that? (Suchet 2009)"

These comments were made in order to raise the profile of dementia and highlight some of the funding needed in order to develop carer support services across the country. All of these contributions from popular sources may serve to influence the way that people conceptualise dementia. While many of these sources could not have directly influenced the data presented in this study, the importance of popular sources in shaping understandings of dementia, both among the general public and health professionals, should not be underestimated.

2.9 Conclusion

This selective review of literature, popular sources and personal accounts has provided academic context for the data which will be presented in the coming chapters. The chapter began by considering two key papers about clarifying concepts in nursing. Thereafter, some previous research about conceptualisation was reviewed. The remainder of the chapter challenged the reader to think about dementia in a number of different ways, leaving behind the personal perceptions with which one starts and considering the different bodies of literature afresh. Historical sources were outlined briefly to provide background. Medical and psychiatric views of dementia were considered with discussion of neuropathology, diagnosis, treatment and prognosis. Thereafter, a social view of dementia was offered, with the presentation of literature on social construction, malignant social psychology and person centred care. Finally, my own personal account was presented, alongside

other accounts from popular sources. These, although not usually part of an academic literature review, were considered to be important, in order to reflect the sources which nurses might draw on in the formation of their conceptualisation of dementia.

CHAPTER THREE

THEORETICAL PERSPECTIVES

3.1 Introduction

This chapter considers the theoretical perspectives which shape this thesis. The work of French scholar Pierre Bourdieu is introduced and the origins and aims of his *Theory of Practice* and the broader ideas of reflexive sociology are explored. Concepts of *field*, *capital* and *habitus* are introduced and their interaction in the Theory of Practice is discussed. Language is also discussed with reference to Bourdieu's theories. After this theoretical beginning the chapter moves to the application of Bourdieu's work in social research and considers how the theories might be used in nursing research and in this study particularly. The utility of Bourdieu's work in shaping this research will be explored and the process of analysis will be discussed. Diagrams included in appendices one, two and three will be used to explain these analytical points. Finally, by way of highlighting the reflexivity inherent in Bourdieu's approach, my own personal views, outlined in chapter two, are revisited and further analysed using a reflexive sociology approach.

Finding a theoretical framework for this study was a challenge. The theoretical underpinnings of the work had to suit the research questions, the clinical settings and the wide range of influences thought to relate to the nurses' conceptualisation of dementia. Furthermore, the theoretical perspectives had to suit my personal feelings about both research and the subject area. Grounded theory, ethnography and phenomenology were all considered as approaches but none seemed to fit the research questions and overall aims of the study, while remaining true to my own

interests in the influences on nurses and the wider social and structural context within which they work. Pierre Bourdieu's writing was introduced to me after much unpicking of the study topic and research questions. His theories, though dense and challenging to read, proved to encapsulate many of the features of the study that I had highlighted and demonstrated a way of bringing information together describing disparate influences. His theory of practice has been used as a framework for sociological research in a variety of areas although rarely in nursing and healthcare research. This framework seemed to be a useful and innovative way of approaching this dementia nursing study.

3.2 Pierre Bourdieu and Reflexive Sociology

Pierre Bourdieu died on 23rd January 2002 at the age of 71. He left behind a legacy of scholarship, combining empirical research with philosophy and was widely regarded during his life as one of the most important contemporary sociologists of his time (Jenkins 2002). Little biographical information about Bourdieu exists as he deplored self-disclosure and refrained from making personal observations, considering these to be individually subjective and devoid of sociological insight (Swartz 1997). The little that is known about him personally relies on his writings and observations made by students such as David Swartz who gained insights from time spent studying under him in Paris.

Pierre Bourdieu was born, son of a postman, in the Béarn region of France, a remote rural area with its own dialect. He moved to Paris to further his studies at the age of nineteen and encountered the French academic elite. Always an outsider in the intellectual elite and in the Parisian social scene, Bourdieu began by studying philosophy before moving on to work as an anthropologist in North Africa (Swartz 1997). His own upward social mobility made him aware of social differentiation and promoted the development of his ideas about social science which were to shape his academic career and his intellectual legacy. He rejected the value neutral positivist

tradition and sought to find a way of combining scientific endeavour with the influences and motivations of individual human action. Bourdieu's acute awareness of the links between social position, politics and research led him to adopt the stance of a critical inquirer, developing his own style of research which sought to challenge social interactions and systems in a way not seen in interpretivist traditions. Crotty (1998) describes critical inquiry as follows;

“... critical inquiry remains a form of praxis – a search for knowledge, to be sure, but always emancipatory knowledge, knowledge in the context of action and the search for freedom. It is in this mood of critical reflection on social reality in readiness to take action for change that critical researchers come to the tasks of human inquiry (Crotty 1998 p159).”

Bourdieu's Theory of Practice and his reflexive sociological approach to research were developed against the backdrop of his social and political awareness and his critical analysis of the social world. Crotty (1998) describes critical inquiry as a “form of praxis”, a description which accounts for Bourdieu's repeated forays into fieldwork and empirical research throughout his career.

When characterizing his own work in the brief space of two words, Pierre Bourdieu wrote of “structuralist constructivism”. This phrase represents his lifelong goal of bringing together elements of structuralist and constructivist thought in a single theory explaining actions and motivations within a social system. According to Bourdieu, objective structures which guide and constrain practices exist alongside individuals. These individuals interact with the structures using perception and thought to shape their interaction, forming alliances and groups in order to advance their own wishes through the use of collective power within the social system. This combination of the objective structures recognised by structuralist thinkers, together with the interactive meaning created by the constructivists, forms the basis of Bourdieu's Theory of Practice.

Pierre Bourdieu's reflexive approach to sociology demands that social scientists critically examine their own social positions as well as those of their research subjects. The required reflexivity was conceived, by Bourdieu, as a rigorous and systematic process which would allow the social scientist to critically assess the research field and gain a degree of objectivity through reflection. Bourdieu's vision of reflexivity is, therefore, somewhat different to the reflexivity which has become part of nursing practice (Burns & Bulman 2000) or that of other research approaches (Wacquant 1989; Woolgar 1988). His project is not personal in nature and does not seek to explore personal responses or self awareness. Rather, Bourdieu's approach requires specific and systematic analysis of the sociological position of the social scientist within the research field. Personal positions, motivations and biases must be taken account of but, in addition, the social scientist must take account of his/her position in the study field, with reference to the fields of power and academia. Finally, the social scientist must also analyse the question being asked and the desire to explore and give meaning to a specific topic. These analytical points form the backbone of the reflexivity of which Bourdieu writes. His reflexive sociological approach seeks to turn sociology back on itself rather than to require individuals to reflect their personal views, motivations and feelings in the quest for sociological knowledge.

3.3 Theory of Practice

Bourdieu's Theory of Practice brings together ideas about institutional and social structures, power dynamics and agency within the social world. The theory can be used to interpret and build an understanding of the actions of individuals and groups of people within a social context. Bourdieu's theory considers group behaviour to be more than the sum of individuals within the group. His theory incorporates the influences of culture, traditions and aspects of structure in explaining group behaviours (Jenkins 1992).

The nurses in this study were each individuals acting in accordance with their personal knowledge, values, experiences and beliefs. The individual interviews gave insight into some of these ideas. Furthermore, discussion in the focus groups also allowed individuals to express personal views and permitted some of these ideas to be contrasted with other group members. The focus groups also allowed some insight into group ideas, as shared and new ideas emerged in the group setting. These aspects of focus group research are discussed in more detail in chapter four. However, using Bourdieu's Theory of Practice to guide the collection and analysis of data was considered a useful additional way of reaching and understanding some of the collective ideas expressed by the nurses. The theory allows data about occupational and workplace culture, societal views of older people and mental frailty, structures of the workplace and social worlds to be incorporated and made explicit in the analysis. These wide ranging influences are incorporated in the Theory of Practice through the concepts of *field*, *capital* and *habitus*. The following section will outline each of these in turn and comment will be made about the relationships between the concepts.

3.3.1 *Field*

Bourdieu introduced the concept of *field* early in his career, developing it through his study of Algerian tribes. He found that structural explanations failed to fully make sense of the interactions within the tribes. While rules or structures were in place they did not fully explain the behaviour of those within the tribes, as they removed some of the social context from the individual actions and disregarded the individual autonomy of the actors (Robbins 1991). Furthermore, the interpretation of the observation of the tribe was influenced by assumptions made by the observers, drawing on their own experiences and social positions. Bourdieu's development of the concept of field was, therefore, in response to his desire to disassociate himself from traditional structuralism and develop a concept which clarified the relationships between traditional structures, social and cultural conditions, while, at the same time, incorporating the agency of the individual (Robbins 1991).

Crucially, the field is a dynamic entity which changes in response to actions of individual and structures within it. Mahar et al. (1990) suggest that;

“The conception of field which Bourdieu uses is not to be considered as a field with a fence around it, or in the American sense of domain, but rather as a ‘field of forces’, because it is required to see this field as dynamic, a field in which various potentialities exist (p8).”

This concept of field can be compared to Goffman’s ‘frame’ (Goffman 1986) but where Goffman, an interactionist, focuses on individual actions and reactions, Bourdieu takes much more account of social and economic processes, incorporating these into the heart of his theory. Bourdieu and Goffman both focus on the fine detail of everyday life (Jenkins 1992) but Bourdieu takes a more structural approach and makes the structures of the social world central to his concept of field (Bourdieu 1983).

The field comprises structures, institutions, activities and authorities which are specific to that field and thus make it a partially autonomous entity. Each person acting within the field can effect change (Bourdieu & Wacquant 1992). Boundaries are challenged as power dynamics shift and individuals change position within the field. Capital, specific to the field, is attached to individuals and is exchanged to promote, and measured to record, positions within the field. Furthermore, habitus also influences the development of the field as culture, traditions and experiences interact to influence the way in which social positions and actions are regarded and the associated capital attached.

Bourdieu’s theory considers autonomous fields existing independently of each other but within the context of a wider relationship with the field of power. Healthcare offers useful examples of these relationships as different specialisms occupy

different positions within the wider healthcare context. Certain specialisms occupy more dominant positions in relation to the field of power, for example, the fields of oncology or cardiology may be deemed to occupy more powerful positions than continuing care of older people.

Finally, the theoretical dichotomy between the fields of production and reception should be raised. This complex theoretical discussion highlights the difference in position between the producer of art, written material or activity and the receiver of such information. This positional difference may be influenced by history. For example, the music of Mozart, created centuries ago will be received within a different context today from both the context of its original reception and the context of its production. That is to say, it is heard neither as the audience would have heard it at its premiere or as Mozart intended it while writing it at his piano. These differences may be influenced by previous experience, time, education, culture or social factors and can pose epistemological difficulties. For example, if it is argued that the social position and structural influences on a producer of work must be fully understood by the receiver of that work, a clear problem emerges. Despite detailed biographical accounts, Mozart's life and motivations can never be fully understood by a listener introduced to the work of Mozart in the 21st century. Bourdieu's theory seeks to make assumptions explicit through reflexivity in an attempt to bridge the inevitable gap between the fields of production and reception (Bourdieu & Wacquant 1992).

The field should be the primary object of study in any research project allowing interactions to be studied within their social context.

“The notion of field reminds us that the object of social science is not the individual, even though one cannot construct a field if not through individuals, since the information necessary for statistical analysis is generally attached to individuals or institutions. It is the field which is

primary and must be the focus of the research operations (Bourdieu & Wacquant 1992 p107).”

The field, therefore, provides a frame through which aspects of social life are examined (Rhynas 2005a). Defining the field for the present study was an important early decision which shaped the nature and parameters of the research. The initial aims of this study centred around understanding the ways in which nurses from a variety of clinical settings conceptualised dementia. Nurses in community nursing practice, acute hospital settings, continuing care environments, mental health hospitals, nursing and care homes were all considered for inclusion in the study. Specific discussion of recruitment to the project features in chapter four. However, the relationships between community nurses and their patients were considered to be qualitatively different to those encounters taking place within inpatient settings. Power dynamics between nurse and patient, organisation of work, interactions with colleagues and structures of the wider care environment were all considered to be differences between inpatient and community settings. For these reasons the community nurses were not included in this study. The field was, therefore, determined to be ‘*inpatient dementia care*’.

This choice of field encompassed a range of clinical settings with different modes of organisation and acuity. The field was expected to be influenced by issues such as personnel, environmental factors, dominant clinical paradigm and organizational factors. However, other factors such as education, the media, science, views of older people and personal experiences were also considered important determinants of the shape of this study field. Within this field actors interact with structures to alter the field direction and change the nature of the field. For example, nurses, doctors, patients and family members all interact within the context of the hospital, legislation and the wider social world. Using Bourdieu’s Theory of Practice, each of these relationships can be made explicit and explored in more detail.

3.3.2 Capital

Definitions of capital can be found in a variety of writing in the social sciences. For the purposes of this thesis, the definitions used centre round the writing of Bourdieu and those commentary texts which facilitate the discussion of Pierre Bourdieu's writings. Capital can be divided into four categories; economic, social, cultural and symbolic (Jenkins 1992). The specific field determines what will 'count' as capital within its boundaries but the four forms of capital are exchanged or accessed as resources by actors within the field.

3.3.2.1 Economic Capital

Economic capital, much as might be expected, covers money, property and labour issues. Despite refuting the predominance of economic arguments in Marx's work (Swartz 1997), Bourdieu also emphasises the importance of economics in creating a simple system of exchange of power, property and labour. Unlike Marx, Bourdieu stresses the importance of other types of capital alongside purely economic forces. Economic capital remains conceptually simple in terms of its creation, retention and exchange within the field. It is also a type of capital which has gained in importance in healthcare settings in recent years with focus moving towards cost effectiveness, cost cutting and value for money in healthcare. Nurses have become increasingly aware of economic issues and the ways in which economic exchanges have an impact on clinical settings. Staffing, drug budgets, funding of care packages and long term care are all aspects of nursing older people which can be related to the exchange of economic capital.

3.3.2.2 Social and Cultural Capital

Social capital is closely related to cultural capital and covers social networks and acquaintances. Bourdieu highlights the possibility that individuals may have multiple social hierarchies and, therefore, hold different social capital within a single social

context (Bourdieu 1992). For example, within a single social setting a post graduate nursing student may play the roles of student, teacher, researcher and nurse. These roles interact and overlap but require the individual to hold a number of positions in a social hierarchy even within the same University department. Cultural capital includes language skills and educational credentials and is arguably Bourdieu's most unique contribution to the discussion of power distribution and dynamics. Bourdieu highlights that;

“certain practices obtain legitimacy in opposition to other practices (Swartz 1997 p63).”

This can be seen when certain cultural practices are subordinated by the emergence of another sub culture. Examples of this can be found in our own social world post 9/11 where the social and power dynamics associated with the wearing of religious attire in public have been markedly changed by world events and prevailing attitudes. Similarly, some nursing practices develop in opposition to other approaches to care. Throughout the presentation of data in this thesis, dichotomies emerge between nurses working in areas of contrasting acuity and those from mental health or general nursing backgrounds. These contrasts contribute to the development of practices and are explored through the nurses' data.

Cultural capital can be embodied in abilities, for example, music or artistic skill. Many of these skills are learned or developed through education or opportunity and, therefore, cultural capital and economic capital can often be linked, although this is not necessarily the case. Cultural capital may also take the form of objects or may be institutionalized through educational credentials.

3.3.2.3 Symbolic Capital

Symbolic capital is the final and most abstract form of capital and involves what Jenkins describes as prestige or social honour. Swartz (1997) describes it as ‘desired capital’ – a form of power which is not explicit but underlies many relationships within the social context leading to status, deference, obedience and inexplicit demarcation of power. This power is seen in individual personal qualities, for example, use of charisma and means of persuasion. It is more clearly demonstrated by rank or social position. These are factors which shape the field in this study, with different professions and nurses of different ranks interacting to shape the dynamics and the boundaries of the field of inpatient dementia care.

These four forms of capital are interconnected and this is particularly evident in advanced societies where many aspects of culture converge. This can be demonstrated, for example, when economics and family structures combine in discussions about childcare and child rearing or the arts and finance combine in corporate event attendance and access to the arts. The specificity of capital in individual fields makes it necessary to analyse the power dynamics and exchange of power in each individual context in order to fully understand the working of that field. Within each field the distribution and significance of capital may vary between actors and this too may be influential. For example, within the study field, educational credentials and achievements may be understood differently and may have different value between the field’s occupational groups. This may be seen when medical colleagues obtain credit for additional academic achievements while these may be less highly regarded within clinical nursing where additional academic qualifications are often poorly understood and their value unappreciated. These subtleties may reflect underlying cultures and historical features of the occupational groups which can be explored further using Bourdieu’s concept of habitus. This concept is examined more closely in the following section.

3.3.3 *Habitus*

The concept of *habitus* represents Bourdieu's explanation of influential aspects of social life which may be unspoken or inexplicit. Cultures, customs and traditions are all incorporated into this theory which seeks to further explain everyday lives and actions of individuals (Webb et al. 2002). Features of *habitus* are not learned from academic texts but become part of an individual's repertoire of behaviour through an iterative process of learning. Family members and those within the individual's social context are imitated without the explicit awareness of the individual. This process of learning through socialization differentiates features of *habitus* from formally learned information (Jenkins 1992). Furthermore, it makes the features of *habitus* difficult to recognise and their significance difficult to measure. For example, manners, ways of walking, tones of voice and ways of approaching people are all implicit examples of *habitus*. A purposeful stride carries a different significance to a relaxed meandering gait. In many cases, these differences are understood and their significance digested without an individual being explicitly aware of the cognitive process underlying the conclusions. *Habitus* often goes unquestioned as understandings are often common to social groups and are part of an inherent cultural bond. This could be described as an embodied reality which binds groups within the social world and forms unspoken bonds between people.

Habitus is an abstract notion. The significance of it is poorly understood and may be particularly important in specific fields. The topic of this research includes discussion of subtle aspects of nurses' understandings, perceptions and ways of conceptualising dementia. *Habitus* may be significant in this regard as nurses may be socialized in the workplace and may develop, through observation in practice, ways of understanding and approaching dementia care. Personal experiences may also be importantly combined with societal views to shape the individual nurse's approach to dementia. For these reasons, the analysis of *habitus*, within the framework of Bourdieu's Theory of Practice, was considered to be particularly important in this study and was thought to have the potential to contribute greatly to the analysis and

interpretation of meaning in the data which may, otherwise, have remained buried within the text of transcripts and observation notes.

3.3.4 Combining Concepts in the Theory of Practice

Each of the three main pillars of the Theory of Practice has been outlined in the preceding pages. While the interaction of some of the concepts has been outlined, the relationship between the three pillars of the theory needs to be clearly explained in order to fully make sense of the Theory and its potential utility in this research. Bourdieu himself explains the interaction in an equation (Bourdieu 1984);

$$[(\text{habitus})(\text{capital})] + \text{field} = \text{practice}$$

This equation shows habitus and capital interacting together directly as individuals seek to gain capital through their actions but are internally regulated by habitus. The field plays a crucial role both in giving the action meaning, setting the goal through the determination of capital and constraining the action through boundaries of field. This equation demonstrates the importance of field and capital working together to create the structures within which individual agency can be dispensed. Habitus regulates agency, shaping the style of behaviours and regulating aspects of cultural coherence within the social world.

3.4 Bourdieu and Language

Bourdieu considers language to be an important means of interacting, expressing and sharing information and feelings. As such, language plays an important part when analysing spoken data. Theoretical aspects of Bourdieu's views of language are, therefore, discussed in the following section. Pierre Bourdieu stresses the importance of language both as a cultural influence and a form of capital which can be

exchanged within the social world. This exchange of capital represents a power dynamic between the giver and receiver of the communication as expressed below;

“The linguistic exchange is also an economic exchange which is established in a symbolic balance of power between a producer endowed with a linguistic capital, and a consumer (or a market), and which is calculated to procure a certain material or symbolic profit (Bourdieu 1982 pp59-60, cited in Snook 1990 p170)”

For example, a nurse discussing medication with a patient has knowledge of the drug and the authority to issue instructions about taking the medication. The patient is the receiver of information and, as such, is relatively powerless. While he/she may refuse to swallow the medication or reject the nurse’s advice, these courses of action would be negatively viewed by the social world. The relative power of the nurse is, as a consequence, reinforced by the social setting in which the interaction takes place. Language is, therefore, part of an activity in which some people dominate others.

Language can also be seen as a means of belonging to a group. Common language helps to bind a group together and use of that language helps to integrate an individual into that community. Within a community there is a linguistic code which serves to make certain language meaningful. The dominant forces within the community control the language of the group and the means of appropriating that language. For example, a student nurse going to a hospital ward may be initially confused by the language used in the setting. They will soon learn and use the language in order to be included in the group. The language used is learned from more senior colleagues who use the language themselves but also have the authority to make changes to the language and pass it on to other group members. These more senior figures may be nurses and doctors within the care setting who are influential in shaping the dynamic of the workplace. The student nurse can not challenge the authority or the language of these figures from a position of relative powerlessness

and the dominant group member therefore shapes the language of the student in this example.

The power of language is not in the words themselves but, rather, in the way in which the social world interprets both the words and their context. Someone who speaks from a position of power will carry more influence than someone who is less powerful but utters the same words. Elements of habitus such as means of address, stature and status will all influence the manner in which language is exchanged. This is important in the study field of inpatient dementia care where information divulged by a doctor may have a different status than that of a nurse or fellow patient. Furthermore, the language of an individual incapacitated by dementia may lack value within the study field. The language used by someone in power must be understood by the audience in order to grant power to that individual. If the language is not understood the power of the person communicating is not recognised by the group. For example, if a doctor gives a complex medical diagnosis using medical terminology, the information may not be received by the patient and the full power of the doctor is not then realised.

This theoretical introduction to the work of Pierre Bourdieu serves as background to the use of his Theory of Practice to shape this study. The remainder of this chapter will explain the ways that Bourdieu's work has previously been used in research and highlight the potential that it may have to help nursing research specifically. Thereafter, the use of Bourdieu's theories in shaping this study will be explored and the organisation of the thesis will be explained. Finally, some reflections on my personal position in relation to the study and the study field will be analysed in order to demonstrate the reflexive sociological approach in action.

3.5 Previous Use of Bourdieu in Research

Bourdieu's writings have been used to shape research projects in the past but rarely in nursing. Swartz (1997) contends that his theories have not received the attention that they deserve in the world of research, perhaps because Bourdieu's concepts are not easily summarised and remain theoretically challenging. Furthermore, the density of the texts and the limited availability of translations of many of Bourdieu's works contribute to the difficulties in accessing his work for widespread research use.

Bourdieu's theories and research approach seek to bridge the divide between the objective and subjective. Nursing research has, at times, found itself caught between the objectivity of biomedical research and the more subjective notions of care and compassion which nursing research has sought to explore. Bourdieu's writings have the potential to offer nurses a theoretical framework which meets the needs of nursing and social care research by allowing analysis of both structural aspects of care and the interactions and relationships within the care setting. In addition, adopting Bourdieu's writing as a theoretical perspective allows flexibility in the choice of research methods. This can be important in nursing research where sensitive topics may be explored (Crossley & Crossley 2001) and pragmatic aspects of research in a care setting must be accounted for in the research design.

The study of relationships within a field and their interaction with the structures and power dynamics of that field are concepts which have long been explored by public health researchers and epidemiologists (Frohlich et al. 2001). Bourdieu's theories have the potential to contribute meaningfully to research in these fields. Furthermore, the primacy of the field as the focus of research allows the identification of patterns of behaviour within a population. This has proved to be useful in the study of sickness absence where a multitude of health related, socio-economic and cultural factors contribute to behaviour (Virtanen et al. 2000) and also in the examination of welfare and support services (Peillon 1998). A Finnish study of medication use chose to adopt a more limited approach to the concept of field and explored only a portion

of the identified field (Lumme-Sandt & Virtanen 2002). This limited use of Bourdieu's approach is acknowledged by the authors; however, the study did raise interesting points in relation to the distribution of capital within the study group. Older people were found to be reluctant to challenge medical professionals about their medication, a finding which could be explored fully using Bourdieu's concepts of habitus and capital.

Bourdieu's theories have been used in social and healthcare research but rarely in nursing research. The theory of practice and the reflexive sociological approach developed by Pierre Bourdieu have the potential to contribute positively to nursing research, offering flexibility in the research methods and a theoretical framework which combines disparate influences on health and healthcare. The following sections will consider how the approach is used in this research and in the subsequent development of this thesis.

3.6 Theory of Practice and this Study

Bourdieu's Theory of Practice has informed this research from an early stage. Before choosing to use Bourdieu's work as a theoretical perspective to guide this study, the research questions were developed and some ideas about data collection were gathered. Pierre Bourdieu's writing provided a useful framework for the final research design and subsequent data analysis. This section of the chapter considers each stage of the research process and discusses the use of a reflexive sociological approach throughout this project. The organisation of a thesis using Bourdieu as a theoretical framework is also discussed.

3.6.1 Research Design

Research design combines four overlapping elements; epistemology, theoretical perspective, methodology and methods (Crotty 1998). In some cases one element

leads clearly to another, for example, a constructivist epistemology informing a symbolic interactionist theoretical perspective, leading to grounded theory methodology and data collection by interview. Using Bourdieu's writing the individual elements are less clear. As outlined in an earlier section, Bourdieu himself defines his epistemology as "structuralist constructivism". With this epistemology and a critical inquiry perspective, there is no specific blueprint for the methodology and methods which follow. The design of this study, therefore, was developed from the field of study. Initial analysis of the field, consideration of the people to be recruited and the desire to collect data which were reflective of the structures and character of the settings, as well as the individuals acting within them led to the choice of data collection methods. Focus groups and interviews were used to gather data from individual nurses and practice was observed through non participant observation in some of the clinical settings. Non participant observation was chosen as Bourdieu rejects the use of participant observation. Awareness of my own position as a nurse, as well as a researcher, was critical in reflecting on the observation data and these reflections were included in the field notes. More detail about these methods is given in chapter four. At the design stage little attention was given to the analysis except to say that Bourdieu's writings would be used to guide this process.

3.6.2 Data Collection and Analysis

Bourdieu's work did not directly influence the collection of the data itself, although initial analysis of the study field did highlight some power dynamics and hierarchies of which I was then aware while collecting data in the clinical settings. It was at the analysis stage that Bourdieu's writing became very important to the direction of this study. My initial intention was to complete preliminary analysis of the data before exploring the data further using Bourdieu's theories. However, early in the analysis process it became clear that Bourdieu's approach had to be an integral part of the analysis process. Aspects of hierarchy, power dynamics and the structural constraints of the hospitals all emerged from the data as key factors and Bourdieu's writings proved useful in both recognising and exploring these factors in more detail. Bourdieu's texts were interrogated further in order to find a 'method' for my

analysis. Using Bourdieu's own writing (Bourdieu & Wacquant 1992; Wacquant 1989) and the commentary texts of Richard Jenkins (Jenkins 1992; Jenkins 2002) the analysis began using the three steps outlined below;

- Consider the relationship of the field in question to the field of power.
- Within the field in question construct a social topology of the positions making up the field.
- Analyse the habitus of the individual actors and the strategies or trajectories produced by interaction of habitus with the constraints of the field

(Jenkins 2002 p86).

In view of Bourdieu's assertions about the primacy of the field in social research it was important to clarify the positions of actors in the field for the purposes of analysis. With this in mind, point number two on the above list was approached first. Despite Jenkins' term 'topology' being somewhat unclear in describing exactly what kind of social mapping was required in order to analyse the data, diagrams were created in order to provide a clear framework for analysis. The initial diagram (diagram one) which explored the positions of actors within the study field was developed over the course of early analysis and is included in Appendix one. This social map displays the positions of the nurse, the individual with dementia and their family and shows dementia to be central to these relationships. The diagram points out a number of relationships which shape the dynamics of the field. Note is also made of some experiences and knowledge which contribute to the character of the field and are influential in shaping interaction between the actors and the structures of the field. This diagram provided a useful starting point for consideration of the structures and relationships within the study field and became the main point of reference for the coding of focus group, interview and observational data.

With data coded according to the relationships and structures emerging from diagram one, further analysis was undertaken in order to explore the power dynamics of the field in more detail. This analysis did not raise new relationships within the study field but, rather, provided information about the quality of the relationships and the exchanges of power which were part of each relationship. This information was brought together in diagram two which is in Appendix two. This complex diagram shows the ways that power is distributed in the study field and ways in which transfers of power occur. Factors influencing the exchanges of power are illustrated and the position of nurse and patient, as central to the field, is clearly demonstrated. This diagram also makes structural aspects of the field explicit and shows ways in which the field is constrained and shaped by these structures. The diagrams themselves were priceless tools in developing the data analysis. While their utility in describing the aspects of the field to a reader or observer may be limited by their complexity and the abstract nature of their content, the diagrams ensured the thorough interrogation of the data and facilitated the exploration of both interactional and structural influences on the field.

Exploring the power dynamics of the field in this way made it possible to return to the data and re-examine it with new eyes. Aspects of the nurse-patient relationship were explored in detail, as well as wider aspects of hierarchy and structure within the clinical settings. Language played an important role in characterizing relationships and power within the field. Using diagram two helped to make the exchanges of power within the field explicit and provided a useful point of reference as the data were further examined.

Analysing the power dynamics and relationships within the study field demonstrated ways in which cultures and prevailing discourses shaped the field. Furthermore, motivating factors, personal influences and influences from the wider social world were made explicit through the development of the diagram and the subsequent reconsideration of the data. As a result of this analysis, a final diagram (diagram

three) was created which explored the influences of the wider social world. This diagram is included in Appendix three. Eight key aspects of the social world were considered; education, ethnicity, religion, medicine, law, economy, governance and the media. These eight factors came from the data and, after making them explicit through the development of diagram three, their influence on the field was explored

Diagram three provides a limited profile of the social landscape against which the snap shot of data for this study was taken. The elements of the social world which are noted, influenced the data and provided social context for the interactions within the field. The status of nurse and doctor, the primacy of medicine as a discipline and the value of diagnosis are all important factors in the data which can be reflected in the wider social world. The image of a society which values older people less, demands more of people cognitively and is preoccupied with risk and litigation is an influential context for this study.

The three diagrams help to operationalize Bourdieu's theories throughout the analysis of the data. Aspects of habitus and the interaction between habitus and the boundaries of the field naturally arose from the data during the course of this three step analysis. The final stage of analysis came at the stage of writing this thesis. The process of writing brought together the extensive data analysis, my own personal positions and motivations and facilitated the emergence of a new way of explaining the nurses' views. This process gave voice to the findings which, until that point, had been hidden within the analysis.

3.6.3 Organisation of the Thesis

The organisation of this thesis also reflects Pierre Bourdieu's influence. The early chapters set the scene in terms of initial motivations for the study and development of research questions from a background in practice. Literature is presented in order

to provide an academic context for the work and make explicit the schools of thought which influence the writing of this thesis. This chapter provides the reader with theoretical insights into Bourdieu's writing which will be used in the exploration of methods and data which come later in this thesis. The data are presented over four chapters. These four chapters represent the four key ways that nurses were found to conceptualise dementia. Each of these chapters presents data from the nurses themselves, together with literature relevant to the topics being discussed. By presenting data and literature together it is hoped that academic influences are made explicit and context is provided for the reader. Personal reflections are offered throughout the data chapters and reflections on my own nursing practice are included on occasion. Finally, the discussion brings together the data chapters and provides opportunity for final reflections on the findings from both personal and professional points of view.

3.7 Reflexivity

Bourdieu's focus on reflexivity requires that the motivations and influences be explored at each stage of the research process. As a postgraduate student the motivation for this piece of work has centred around the requirements of a doctoral thesis. The scale and style of the project reflect this aim and the style of writing is also intended to meet the requirements of an academic audience. Personal interests in the topic were outlined in chapter two and these are reflected in the initial research questions, the choice of approach and the data collection for this study. My views are influenced by my experiences as a registered nurse caring for older people. My observations in the clinical settings reflect this position as 'insider' (Morse 2000). This position as 'insider' may be beneficial in promoting understanding of the setting but also has the difficulty of 'taken for granted' understandings. This was notable during the data analysis when an observer questioned a piece of data which had been taken for granted in my analysis. Bourdieu's strategy of reflection requires such motivations and personal positions to be made explicit during the research process in order to ensure that understandings take account of disparate contributory influences.

As an observer in mental health continuing care wards, the position of ‘outsider’ was more appropriate. The mental health environment was very different to the culture and organisation of a general medical ward and, as such, was effectively unrecognisable to me. In these settings I had a different view of proceedings. My personal feelings and ‘fresh eyes’ gave me a view of practice which was unrelated to personal practice in the area. However, my background as a registered nurse contributed to the data generated from my observations and coloured my vision of what was before me. For example, this was evident in my field notes where I have noted discomfort about the high level of noise in the clinical setting which was in direct contrast to the typical medical ward.

Finally, my personal experience of dementia in my own family is carried with me throughout this study. The experience with my grandmother, described in chapter two, shapes my personal response to dementing illness and my view of the contributing nurses’ opinions. Personal reflections are included, where appropriate, in the data chapters as my own views contributed to my interpretation of the data.

3.8 Conclusion

This chapter has considered the theoretical perspectives used in this thesis. Pierre Bourdieu’s writing has been introduced and his Theory of Practice explained. Elements of a reflexive sociological approach have been considered. Concepts of field, capital and habitus have been discussed and Bourdieu’s views on language have been outlined by way of explaining its importance in this study and the wider social world. Some previous research studies using Bourdieu’s theoretical approach were briefly considered. The use of Bourdieu’s writing in shaping this study was described. Aspects of research design were discussed before focussing on the process of data analysis. Diagrams developed in order to help with the data analysis were presented and their utility highlighted. Finally, the organisation of this thesis, using

Bourdieu's principles, was outlined and remarks were made about reflexivity in the research process.

CHAPTER FOUR

METHODS – CONDUCTING THE STUDY

4.1 Introduction

This chapter discusses the ways in which this study was conducted and issues which emerged during the work. The chapter follows the project from its beginnings with the development of research questions, through the process of research design and the tumultuous practicalities of gaining entry to the NHS hospitals and collecting data. Thereafter, issues of analysis are discussed with reference to the influences of Pierre Bourdieu's writings. Personal reflections on the research process and my own positions as nurse, researcher and family member within the study field are offered.

Work began on this study in the autumn of 2002 following the completion of MSc by research. The first year of study involved development of the research questions, preparation of the research design and culminated in the presentation of a research proposal which formed the basis of transfer to formal PhD candidate registration. Data were collected between March and November 2004. Following a period of maternity leave, analysis began in the autumn of 2005 and took place on a part time basis over the following three years with a further maternity break midway through the analysis process. The interruptions to study slowed the analysis process and influenced the study in ways which will be outlined throughout this chapter.

4.1.1 Preparing the Research Design

The research design is a plan which takes the researcher from the initial topic of interest to final conclusions (Yin 1989). This project was developed from questions arising in nursing practice and refined during the period of MSc studies, as outlined in the introduction to this thesis. During the first year of PhD studies, the questions were developed further and the research design was considered in depth. Blaikie (2000) suggests that;

“the approach to research has to match the requirements of the research questions posed (Blaikie 2000 p38)”

The research questions were, therefore, considered in some detail before clear methodological plans were developed. These questions were outlined in chapter one and explore nurses’ ideas about dementia and how those ideas relate to care and care planning. Definitions of research design vary across the literature. Blaikie (2000) outlines his definition of research design being;

“the process of making all decisions related to the research project before they are carried out. This involves anticipating all aspects of the research, then planning for them to occur in an integrated manner (p21).”

This definition strikes fear into the heart of the novice researcher! Notes from my reflective diary of this period demonstrate my own concerns about my ability to anticipate the research process ahead and adequately anticipate, without previous experience, some of the difficulties which could arise.

4.1.1.1 Qualitative Methodology & Research Design

The decision was made at an early stage, to take a qualitative approach to this project as the exploratory nature of the topic did not lend itself to quantitative enquiry. The specific qualitative approach was more difficult to determine and, as outlined in the introduction to chapter three, a number of methodologies were considered before Bourdieu's Theory of Practice was adopted as a framework for this study.

Kvale (1996) highlights the difficulty of fitting interpretive research which develops from the data into a predetermined research design. This concern was very real to me as I sought to find an appropriate design for this project. It seemed appropriate from the outset that data generated in response to the first research question, about nurses' conceptualisation of dementia, should influence the direction of enquiry of subsequent questions on care and care planning. Grounded theory was considered as a methodology which could support this dynamic and developing approach to the research project. From its roots in symbolic interactionism, grounded theory has taken a number of forms (Dey 1999). Glaser and Strauss (1967) suggested that grounded theory offered social scientists an approach to research which was both systematic and also open to interpretation. The approach was not prescriptive but rather served as a framework for research in the social sciences. Grounded theory has become a well established research approach (Morse 2001). It has proved very popular in nursing research although the standard of some of this body of work has, at times been criticised (Benoliel 1996). This popularity may stem from the fact that grounded theory offers researchers pointers as to how the research might be carried out. This was appealing to me as I sought a methodology for this project. Grounded theory offered a means of refining the research topic, identifying social influences, carrying out the data collection and analysing the data. Thereafter, grounded theory also offered a means of knowing when to stop collecting data and develop theory. To a novice researcher, these steps were a tempting guide to the research process. However, I became unclear how an initial round of data collection using a grounded theory, purposive sampling approach could be connected to subsequent data

collection. I was very keen to bring in nurses from a variety of clinical areas and could not be sure that I could take views, ideas and opinions gathered in one clinical area and transport them to another area to be unpicked further by a different group of nurses. Furthermore, I was anxious that data gathered using a grounded theory approach would miss some of the structural and environmental factors which I suspected influenced nurses' conceptualisation of dementia. Eventually, after much consideration, grounded theory was left behind and Bourdieu's writing became the major influence on the research design of this study. Reflecting on this decision as the research process comes towards an end, it seems that grounded theory could, indeed have proved a useful framework for this study. The shape of the research and the methods of data collection and analysis would have been different but the questions could, I believe, have also been answered using this approach. However, Bourdieu allowed the exploration of factors which may have been more difficult to uncover using grounded theory and permitted structural aspects of the workplace, social attitudes and expectations to become explicit parts of this study's findings.

More limited consideration was also given to ethnomethodology as an approach for this work. The importance of observing the nurses in their work was thought to be crucial to the understanding of nursing care and care planning. However, the focus of this project from the outset, was primarily to understand how nurses conceptualise dementia. For this aim to be fulfilled, it was necessary to speak to nurses and understand their views before observing them in their work. An ethnomethodological approach would not have allowed this to unfold in this order with ease as the observation would have been hampered by remarks made by the nurses during focus groups or interviews. For this reason, ethnomethodology was not pursued as a methodological approach. Phenomenology was not considered in any great detail.

The theoretical underpinnings emerging from Bourdieu's *Theory of Practice* demand a reflexive approach to research, as outlined in chapter three. Thorne and her

colleagues, writing in 2004, highlight how nursing research has started to adopt more imaginative theoretical backdrops in response to current research interests.

“Over time, rather than enforcing methodological orthodoxy to traditions that did not quite fit the emerging qualitative nursing scholarship, nurses began to articulate distinct methodological approaches designed to fit the kinds of complex experiential questions that they and other health researchers might be inclined to ask (Thorne et al. 2004 p2).”

While the use of unorthodox methodological approaches may allow theory to inform research questions more appropriately, the ‘rulebook’ associated with more traditional qualitative approaches does not exist. The links between theoretical perspective, research methods and creation of new knowledge are not prescribed but have to be developed. New routes need to be found through the morass of research design. In this project, the tensions between the pursuit of a truly reflexive sociological project as outlined by Bourdieu, my own personal desire to be ordered in my study approach and the research design texts which highlighted the need for detailed advance planning, led to some of my deliberations while formulating the final study design.

Denzin and Lincoln (2000a) have a rather more flexible definition of research design which outlines the aspects of research which should be included but also takes account of the dynamic nature of social enquiry highlighted by Kvale.

“A research design describes a flexible set of guidelines that connect theoretical paradigms first to strategies of inquiry and second to methods for collecting empirical material. A research design situates researchers in the empirical world and connects them to specific sites, persons, groups, institutions, and bodies of relevant interpretive material, including documents and archives. A research design also

specifies how the investigator will address the two critical issues of representation and legitimation (Denzin & Lincoln 2000a p22).”

With this definition in mind and Bourdieu’s writings as a theoretical backdrop, the research project was planned and decisions were made in order to take the project forwards.

4.1.2 Choosing Contributors

Choosing a sample group is crucial to the research project. Some theoretical frameworks or research approaches outline clearly the approach to sampling which should be taken. For example, grounded theory employs a system of constant comparison which seeks to ensure that all aspects of a given topic can be explored (Charmaz 2000). Other research approaches offer less clearly defined guidance in terms of sampling. The work of Pierre Bourdieu focuses the research on a specific field of study. As outlined in the previous chapter, ‘inpatient dementia care’ became the study field and this directed thinking about the sample group. Initially hospital and nursing home settings were considered as potential recruitment centres. Community services were discounted as they did not fit into the field of inpatient care settings. A large list of potential hospital wards, nursing homes and specialist inpatient units was drawn up from personal knowledge and health authority websites and consideration was given to the patient mix, staffing and potential variations between the settings. This process included reading information about the care settings, visiting some of the potential target wards and homes and speaking to nurse managers in order to gain an overview of the services, their client groups and staffing levels. This all contributed to a process of purposive sampling. Purposive or theoretical sampling is described by Denzin and Lincoln (2000b) as a system whereby researchers;

“seek out groups, settings, and individuals where and for whom the processes being studied are most likely to occur (Denzin & Lincoln 2000b p370).”

For this study it was important to find a setting where nurses regularly interact with older people who have dementia and where the nurses were likely to be able to meet as a focus group to explore their ideas about dementia. The choice of focus groups as a method of data collection will be discussed later in this chapter. It was also considered beneficial to explore the experiences of nurses working in a range of clinical areas, as people who have dementia are cared for in a wide range of care environments. Finally, Bourdieu’s writing raised the potential importance of education, workplace culture, socialisation and wider structural aspects of the environment in shaping the ideas of the nurses. This meant that it became important to consider the educational background and professional registration of the nurses and the different aims and objectives of the care settings in determining which areas should be used as study sample areas.

In order to include registered nurses with a variety of experiences and educational backgrounds, nurses of various clinical grades were identified. The final sample comprised thirty eight nurses who agreed to contribute to either a focus group or interview. The specific data collection methods used are explained later in this chapter and a comparison between the planned methods of data collection and the actual data collection completed is outlined in Figure 2 on page 95. Nineteen of the contributing nurses participated in focus groups while a further fifteen ward nurses and four Charge Nurses contributed through individual interviews. Following initial data collection, the majority, but not all, of the contributing nurses were observed in practice. A table detailing the backgrounds of the thirty eight contributing nurses and Charge Nurses is included in Appendix four. Specific inclusion and exclusion criteria for recruitment to this study are explained in section 4.3.1.

Nurses working in care settings with older people in two geographical areas of central Scotland were chosen. One was a large urban centre with a wide range of specialist services while the other drew patients from rural areas and smaller towns. The hospitals in the second location were district general hospitals with distinct medical and psychiatric services but a more limited range of specialist units. Four key areas were identified in each geographical centre as follows;

- ◆ Acute medicine of the elderly
- ◆ Medicine / Rehabilitation for the elderly
- ◆ Mental Health of older people – assessment areas
- ◆ Mental Health of older people – long stay units

The four settings included two staffed typically by registered general nurses and two staffed by registered mental health nurses. There were a few nurses in some settings who were dual trained but the ethos of each setting was determined by the structure under which it was run and the predominance of one registration type. For example, mental health settings were run within the structures of mental health care policies and administration. They included psychiatric consultation and were staffed by nurses who were registered mental health nurses. The four settings also represented a range of lengths of stay and clinical focus. Acute areas were largely short stay units with people admitted for acute care who were either discharged or moved to another area after the initial period was over. This was typically anything from a couple of days to one month in duration. Mental health assessment areas were also intended to cover patients staying up to one month. The medical and rehabilitation units catered for those older people recovering from acute ill health or undergoing physiotherapy and occupational therapy prior to discharge. These patients were in hospital for longer periods, ranging from a number of weeks to some months. The final sample location identified was continuing care. Continuing care of older people takes place in both general medical and mental health settings. However, examination of the settings established that those in medical continuing care settings had complex

medical needs and relatively few had dementia. When dementia was present it was not the focus of care and was seen to be incidental to the other underlying pathology. For this reason, mental health continuing care areas, which focus almost entirely on those with dementia, were chosen as sample settings. Patients in these areas typically stayed from admission until their death – for many a period of several years.

This range of clinical settings was chosen as potential places from which to recruit nurses. The decision to use focus groups for data collection, which will be discussed later in this chapter, meant that data collection in nursing homes would be difficult as only one registered nurse is, typically, on duty at any given time. Furthermore, the structural and organisational aspects of nursing homes were considered to be different to those clinical areas operating under the NHS. The importance placed on workplace culture, organisation and structure by Bourdieu's writing led to the decision not to sample from nursing homes in this study.

4.2 Ethical Issues and Access

Having identified the potential sample areas, the process of obtaining access to those areas began. This process proved to be more arduous than expected and, despite having made initial contact with nurse managers and Charge Nurses in the spring of 2003, it was not until early 2004 that data collection could begin.

Prior to formal access processes beginning, contact was made with nurse managers in the identified recruitment sites. Meetings were set up in order to obtain practical information about the numbers and types of staff on wards, timing of focus groups, entry to the ward for information giving and consent procedures and practical elements of the data collection processes. These meetings were informal but sought to ensure that information needed for the formal access approval submission was accurate and realistic. Furthermore, it was beneficial to ensure that nurse managers

and Charge Nurses in the potential study areas had both heard about the study and were generally interested in it, in order to help the formal access processes.

4.2.1 Ethical and Management Approval

There were two distinct processes involved in gaining access to nurses and patients within the hospital. These processes are necessary in order to safeguard NHS patients and staff and it is right and proper that researchers should adhere to these procedures. Attention is given to any potential harm or distress which could result from the research and also the level of ‘research burden’ in clinical areas where patients and staff may be over-researched. Permissions must be granted by the appropriate ethical review committee and by the management of the specific hospital trust involved in the study. The two systems must be completed in tandem as the ethics committee requires that management approval is in place and hospital management requires that ethical approval has been granted before it is possible to proceed.

Nurses and their conceptualisations of dementia are the focus of this study. The observation phase of the study involves watching nurses in their practice with patients who have dementia. As such, this study could be considered to include patients who may be described as ‘vulnerable’ by virtue of their potentially limited understanding of the research or their limited decision-making capacity. For this reason, application was made to the multi-region ethics committee (MREC) which reviews applications for any research including vulnerable adults. The application was handled very efficiently and, following MREC review in early August, some recommendations were made. These recommendations surrounded the consent procedures which had been suggested for the dementia patients. Informed consent will be addressed in detail later in this chapter. MREC also requested that provision be made to support nurses who became upset by discussing the subject of dementia. This was subsequently covered by making available to each nurse, information about the ‘Alzheimer’s Scotland: Action on Dementia’ telephone helpline to each nurse.

Some other minor amendments were made to forms and MREC approval was granted in mid September 2003.

While obtaining initial MREC it was also necessary to seek support for the project from within the hospital trusts. Consultant Physicians and Psychiatrists had to be informed and their support secured for the research taking place with their patients and in clinical areas under their control. Furthermore, each trust required a senior nursing figure to support the application. Organisational issues within the trusts, regular changes in systems and personnel made this process rather time consuming and frustrating. A second layer of ethical approval had to be sought from the two local research ethic committees (LREC) who deal with applications in their locality. This was submitted in November 2003 and permission was obtained before Christmas. Correspondence with the ethics committees was efficient, with materials exchanged within predetermined timescales. Management approval from the individual hospital trusts was a more haphazard and time consuming process which involved, in some cases, chest x-rays, occupational health reviews and invitations for me to attend manual handling training! By early 2004 all the necessary permissions were in place and data collection could begin.

4.2.2 Local Access

Access to individual clinical areas was obtained, firstly, through meetings or telephone conversations with clinical nurse managers and then through direct contact with Charge Nurses. This was straight forward and appointments were readily made for information giving sessions, consent procedures and focus groups. The Charge Nurses were all supportive and showed an interest in the study. This helped to boost confidence prior to data collection and also helped me to remain positive when staffing difficulties repeatedly disrupted data collection plans.

4.3 Recruitment

Nurses were recruited to the study group after consideration of the duty rota on the ward. This very practical constraint had the advantage of ensuring that there were usually nurses on duty who were of different grades and had different clinical experiences and the sample was, therefore, diverse. This diversity was thought to be beneficial in order to include nurses with varying experiences, educational backgrounds and influences on their views of dementia. The rota was considered in collaboration with the Charge Nurse and a date was set when other ward arrangements were considered unlikely to impede attendance at the focus group. For example, ward round days, staff training days and days where large numbers of staff had leave were usually avoided. In collaborating with the Charge Nurse the potential exists for certain nurses to be put forward for the focus group and others to be sidelined. The Charge Nurse could, therefore, be seen as a gatekeeper in recruiting nurses to the study. In order to alleviate this problem, inclusion and exclusion criteria were discussed with the Charge Nurses and the exploratory nature of the study was highlighted. Charge Nurses appeared to be governed more by the practical aspects of ward staffing and skill mix than by specific nurses' contributions. Focus groups were arranged for the overlap time when both morning and afternoon staff were on duty and staff could, therefore, be released to attend the group. Information sheets and consent forms were delivered to the ward and completed in advance of the focus group.

Patients were more challenging to recruit to the study as their involvement was determined by their interaction with the nurses. No access to medical notes was requested and no diagnostic tools or rating scales were used to ascertain which patients might be considered to have dementia. Nurses were asked to identify those they considered to be dementia patients. This identification procedure has the obvious flaw of clinical inaccuracy. However, it allowed an insight into the care of those patients considered by nurses to have dementia and, who were, therefore, cared for as 'dementia patients'. The focus of the study remained the nurses and the period of observation which followed the focus group sessions was intended only to provide

context and further understanding of information given by nurses during focus group sessions. The observation only included the main ward areas and did not include any 'behind the curtains' observations of nurses with patients. Patients were given information sheets and consent forms in advance of the observation sessions. Patients who had not formally consented or whose consent was not ongoing were not observed and I walked away from a number of encounters on this basis. Consent procedures will be discussed in detail in a following section.

4.3.1 Inclusion / Exclusion Criteria

Sampling in qualitative research is not related to power calculations or determining how many participants are required in order to make the results generalisable. However, inclusion and exclusion criteria are still helpful in setting parameters for participation in the study. This study did not employ stringent criteria but did have a few general guidelines which were helpful in shaping the sample group. Those nurses included were;

- Registered nurses
- Those nurses who worked permanently on the target ward
- Freelance staff who worked on the target ward regularly (average more than 1 shift per week)
- Adaptation nurses registered abroad and working towards registration in the UK through NHS employment

Those excluded from the study were;

- Un-registered staff
- Those who had worked in target wards for less than 2 weeks

Student nurses were neither included nor explicitly excluded from the study but no student nurse showed an interest in this study.

The inclusion and exclusion criteria for patients during the observation phase were more complex and were partially determined by the ethics committee policies. Those patients included in the observation phase were;

- Identified by nurses as having dementia
- Able to understand the information sheet and consent to participation
- Able to give ongoing consent during subsequent ward visits (fully explained later in this chapter)
- Not undergoing any intimate procedure but were interacting with nurse(s) in public ward areas

Those excluded were;

- Not identified as dementia patients
- Identified by nurses but were unable to understand the information or consent to participation
- Patients who had previously consented to participation but, due to fluctuations in condition, were unable to give verbal consent to the researcher during subsequent visit(s).
- Consented patients undergoing intimate procedure or interaction of a private nature with the observed nurse.

4.3.2 Practical Challenges of Recruitment

The recruitment outlined was carefully planned to fit as easily as possible with the ward routine. Choosing the period after lunchtime when the wards had both early and late shift staff appeared to be the most appropriate time to run the focus group. However, the reality was somewhat different. In many cases nurses did double shifts. This meant that although the duty rota showed a member of staff in both the morning and afternoon, this was actually one individual and, therefore, there was no staffing overlap. While raw duty numbers showed four nurses in the morning and three in the afternoon, this rarely translated to seven staff during the changeover period. As a cost

saving measure, many agency staff were employed only until the afternoon staff arrived and not for the full changeover period. Equally, staff were allowed to take back time due to them or attend training sessions during this early afternoon period. Finally, many of the nurses themselves 'budgeted' this time for catching up on paper work or completing time consuming tasks with patients such as complex dressings. As a consequence, it was very difficult to ensure attendance at the focus groups despite regular phone calls, reminders and prompting. Many groups were cancelled over the data collection period. In some study areas, nurses were drawn from more than one ward area and, while this should have increased numbers of nurses available, it rarely worked out on a practical level, as one ward was always overstretched and nurses were often pulled from one ward to help out in another clinical area.

On some occasions, staff agreed to attend a focus group despite that meaning that the ward would be left significantly short of staff. This proved to be an ethical dilemma for me as a nurse researcher. In some instances, I asked the nurses directly if they were happy to leave the ward, given the circumstances. Sometimes a change of venue to a room within the ward area alleviated the difficulty, as the group could have been interrupted should the nurse's attention have been required on the ward. On one occasion, I declined the nurse's attendance when the ward would have been left without a registered nurse for the duration of the focus group.

A final barrier to recruitment was the focus group method itself. Kitzinger and Barbour (1999) suggest that a discussion group can sometimes be intimidating for individuals. This was borne out in practice when a small number of nurses refused to take part in a focus group because the group was comprised of peers and they were nervous of speaking in front of the group.

4.3.3 Consent Issues

Informed consent is a prerequisite for conducting healthcare research. Beauchamp and Childress (1994) suggest that ‘informed consent’ has two defining characteristics; firstly, adequate information must be given in a form which can be readily understood and, secondly, the individual must have the ability to make a judgement about participation and must be allowed to make that judgement without coercion. Research participants must be informed about the study, told about potential benefits and problems associated with their participation and given adequate time to consider the information before consenting to take part. After a consent form is signed they must be given the opportunity of a ‘cooling off period’ in which they can change their minds about participation. These procedures are set out clearly and enforced by ethical review committees. (Beauchamp & Childress 1994)

4.3.4 Consent Issues for Nurses

The consent and information sheets given to nurses participating in this study are shown in Appendix five. In line with the ethics committee requirements, information sheets were given to nurses on the wards during the week prior to focus group or interview sessions. Consent forms were completed on a subsequent visit to the ward, usually two days prior to the focus group. This system was time consuming to implement correctly and, despite best endeavours, did have limitations. The nurses who were consented for a focus group were not always the nurses who attended the planned session! As a result some nurses had received information sheets but had not been formally consented a full 24 hours prior to the focus group. This fell short of the standards set by the research ethics committee. This problem emerged during both the first and second focus groups and raised important issues about the procedures being used to ensure informed consent in this study. The nurses in these cases did participate in the focus groups as, despite the absence of a ‘cooling off period’, their presence at the group was taken to show their prior intention to participate in the data collection session. Consent forms were completed before the start of the groups in all cases. These were stored in a locked filing box in line with ethics committee

guidelines. After focus group two, procedures were amended and larger numbers of nurses were consented on the ward during the week prior to the planned focus group. This solution ensured that the 'cooling off period' was in place but led to the concern that some nurses were consented far in advance of the groups and others, who were consented, did not actually attend a group.

4.3.5 Consent Issues for Patients

The issue of informed consent in a study including dementia patients is particularly challenging and must be dealt with stringently. The focus of this study was the nurses and no note was made of any patient details. However, the patient's interaction with his/her nurse was observed and informed consent was, therefore, sought. The research ethics committee insist on the same system of information sheets, written consent forms and 'cooling off periods' for people who have dementia. In addition, an information sheet for visitors and family was produced which could be left at the patient's bedside for interested visitors to peruse and, in line with advice from experienced dementia researchers, posters displaying my photograph were displayed throughout the study wards in order to act as a reminder to the patient (Wilkinson & Cook 2003). These resources are included in Appendix five.

Observation as part of a qualitative research study is an ongoing process which may involve multiple contacts with an individual. As such, it may be necessary to ensure consent is also an ongoing process rather than a single event prior to the start of a study (Kayser-Jones & Koenig 1994). Competence can not be ruled out simply because of the diagnosis of dementia. While some researchers suggest that standardised tools to judge competence will solve problems of uncertainty in this area (Marson et al. 1994; Morris 1994), others suggest that competence depends on the nature of the decision to be made (Kayser-Jones & Koenig 1994; Shah & Dickenson 1999). An individual may not be competent to make decisions about the sale of a house but may be capable of understanding information about some

research projects. Bartlett and Martin (2002) suggest that assent of a representative of the patient may be considered appropriate when informed consent is not possible. The debate about proxy decision making along with discussions of advance directives and guardianship orders are prevalent in the literature (Bartlett & Martin 2002; Berghmans 1997; Kapp 1994; Sachs 1994; Warren et al. 1986).

4.3.6 Process Consent

The importance of being able to include people with dementia in research reaches far beyond this study. While the focus of this study is the nurses, many other projects seek to explore the views of people with dementia and develop research partnerships with older people. Traditional models of research and consent procedures can stand in the way of participatory research with older people. Many researchers, like myself, are forced to ensure that consent procedures meet ethics committee standards rather than meeting the needs of people with dementia (Dewing & Pritchard 2004; Grout 2004). In response to this difficulty, and as part of a drive towards ‘person-centred care’, a method of process consent has been developed. While this topic is evident in the literature in the early 1990s, the dementia specific work has mostly emerged more recently through the work of Jan Dewing (Dewing 2002; Dewing 2007). Process consent currently involves five elements which can be completed in any order by the researcher through the formation of a relationship with a dementia patient. They are noted below;

Figure 1: Process Consent Method

Background and preparation
Establishing the basis for capacity
Initial consent
Ongoing consent monitoring
Feedback and support (Dewing 2007 p15)

Each stage involves detailed individual interaction with the patient. This method of consent is intended for use with people who might otherwise be unable to consent to research. The ethics committee insisted that all patients in this study be able to consent using formal consent processes. However, the ability of people with dementia regularly fluctuates and a form of process consent was used, in addition to the standards set by the ethics committee. Each patient received the standard printed material but, in addition, received an appropriate verbal explanation. In many cases this was repeated in different forms on a number of occasions. Following initial formal consent procedures, each patient's consent was monitored on each subsequent visit and sometimes at regular intervals throughout a visit. For example, some individuals were able to retain information about my attendance on the ward for the whole period of time I was present. Others demonstrated clear changes in mood or lack of recognition, which prompted a further interaction regarding consent. This was particularly true in long stay areas. After each observation session the patients were individually thanked for their participation and some general feedback was given about the usefulness of the data generated during the session. This approach could be considered unnecessary in view of the written consent granted by this group of patients. However, it satisfied my own desire to enhance the participation of people with dementia in this project and ensure, as far as possible, that consent was informed throughout the study.

Throughout data collection a number of nurses questioned whether the consent of patients was necessary in order to observe the nurse in his/her practice. My own view was that the interaction of nurse and patient involved both parties and consent should, therefore, be sought from both parties. However, in the continuing care wards, it was very difficult to obtain formal consent from individuals in line with ethics committee guidelines. As a result, it was only possible to observe a limited number of patients. This made the observation difficult as it became a challenge to remain in the background while also observing the whereabouts of a small number of individuals, many of whom were wandering throughout the ward. I had to walk past 'unobservable' patients in order to reach those who had agreed to participate.

Inevitably, the data reflect observations made throughout these long stay wards and are not as particular to the consented individuals as initially intended. This situation was unsatisfactory and reflects my own inexperience as a researcher. Any future work of this type in continuing care settings would require more sophisticated consent procedures utilising process consent more fully and making it central to the whole project.

4.4 Data Collection Methods

The choice of data collection methods was made at the research design stage. The research questions required nurses to ‘brainstorm’ their ideas about dementia and it was considered beneficial to do this in a group setting where individuals could contribute their ideas and they could be debated within the group. Focus groups are billed as being particularly useful in helping to;

“understand how individuals conceptualise and categorize phenomena (Stewart & Shamadasani 1990 p141).”

They are considered to be helpful ways of exploring topics which might be imprecisely defined or not thought out in detail. As such, they appeared to be a useful method of data collection to use in addressing the study’s research questions.

Charge Nurses were considered important in shaping some of the nurses’ ideas and implementing them in the workplace. It was considered that Charge Nurses may influence the dynamics of the focus group so the decision was taken to interview those nurses after the ward focus groups were complete. Finally, it was considered important to observe the nurses in their practice with dementia patients in order to collect information about structural aspects of the workplace, practical challenges and to watch information generated in the focus groups emerge in nursing practice.

The observation phase of the study was intended to ‘fill in the blanks’ where questions had emerged during the primary data collection sessions. During the course of data collection the plans changed significantly. Many more interviews were completed than originally planned as the practical challenges of running focus groups in busy hospital wards eventually took their toll on the data collection plan. One group of nurses refused to be observed and this also changed the data set slightly. Below is a table outlining the data collected from each study area and reflecting changes in the initial data collection plan;

Figure 2: Data Collection Plan and Actual Data Collected

Venue	<i>Planned Focus Groups / Interviews</i>	Actual Focus Group / Interviews	Observation	Charge Nurse Interview
Acute Medicine	<i>2 x Focus Groups</i>	1 x Focus Group 6 x interviews	10 hours	No C/N in post
Medicine/ Rehabilitation	<i>2 x Focus Groups</i>	2 x Focus Groups 5 x interviews	15 hours	2 x C/N interviews
MH - Assessment	<i>1 x Focus Groups</i>	1 x Focus Group (joint with Cont Care)	Nurses Refused	1 x C/N interview
MH – continuing care	<i>2 x Focus Groups</i>	1 x Focus Group (joint with Assessmt) 4 x interviews	27 hours	1 x C/N interview
Total	<i>7 x Focus Groups</i>	4 x Focus Groups 15 x interviews	52 hours observation	4 x C/N interviews

The following sections outline some of the rationale for the choice of data collection methods, practical aspects of using these methods and strategies for combining data from these diverse sources.

4.4.0.1 Data Gathering – Topic Guides

The data generated in both focus groups and interviews were shaped by use of a topic guide which can be found in appendix five. At the start of the project the topic guide was created from reading literature, reviewing pilot data and reflecting on personal experiences as a nurse and family member of someone with dementia. The guide was then reviewed and amended as necessary after each focus group in order to reflect information thought to be significant or directions worthy of further exploration. These topic guides then provided the basis for use in individual interviews when it became necessary to complete more interviews in place of focus groups as outlined above. Data were generated in the focus groups using the topic guide as a basis for the initial discussion but the groups and subsequent interviews took considerable direction from the participants. Topics raised by participating individuals were explored and added to the guide for future use if appropriate. The final stage of data generation was the observation phase. An observation guide was developed for use in the clinical areas but was used flexibly as the needs of patients and staff allowed. The observation guide is also in appendix five. More fulsome discussion of the research methods and the rationale for their use is given in the following sections.

4.4.1 Focus Groups

From the early use of group interviews in 1920s psychology research (Bogardus 1926), this method moved into the field of marketing and was used by Merton and his colleagues in their well documented analysis into the effect of wartime propaganda on members of the general public (Merton et al. 1956). From this point forward, the development of the focus group took place in the two very different fields of marketing and social science. This dual development has both confused and, at times, clarified the literatures. In some cases, the literature has become very mixed (Dilorio et al. 1994) with researchers using marketing strategies to defend their use of focus groups in the very different world of social research. While market researchers often use focus groups within a positivist tradition, the use of focus groups within the social sciences has been within a more interpretive paradigm (Reed

& Payton 1997), taking into account the social and cultural context of participants (Kitzinger 1994) and requiring the researcher to interpret the data within this framework.

Kidd and Parshall suggest that;

“focus group methods developed and matured outside of the major methodological traditions of qualitative research (Kidd & Parshall 2000 p296).”

This may account for some of the uncertainty about where focus groups fit methodologically within the social research context. Some of the literature describes focus groups as a methodology rather than a research method (Kitzinger 1994; Knodel 1993). However, no explanation of this terminology is given in the texts and the descriptions appear to be of a method which might be employed within a variety of methodological traditions. Focus groups have gained popularity in recent years (MacLeod Clark et al.1996), particularly in health, social and evaluation research and have become an established method of qualitative data collection (Jowett 1996).

4.4.2 Group Dynamics and Interaction

The group dynamics and interactions within each individual group are unique to that group and play an important role in generating the data gathered from the group.

“Much of the power of the focus group as a method of inquiry grows out of the spontaneity and synergy of the group dynamic (Stewart & Shamadasani 1990 p141).”

Interaction within the group is a definitive aspect of the focus group method and allows focus groups to generate information and insights that would not be gained through individual interviews with group participants (Krueger 1988; Morgan 1997).

4.4.3 Group Size and Hierarchy

Group size and hierarchy within the group are frequently mentioned in terms of the group dynamics (MacLeod Clark et al.1996). The texts on focus groups tend to suggest that the numbers of people participating should reflect the purposes and subject of the focus group (Knodel 1993; Morgan & Krueger 1993). Many agree in suggesting that groups range in size from 4 – 9 people depending on the situation and the nature of the group. This study set out to achieve this through the recruitment of between eight and ten nurses to each focus group. Nurses were usually recruited from a number of wards in order to achieve this. However, group numbers varied considerably with one group only having three members. The dynamics of this group were markedly different to other groups, with many instances of the group splitting into a pair of participants and one individual. After reviewing the data from this group it was decided to set a minimum number of four participants for future groups. It became clear that, in some clinical settings, this minimum number of participants could not be reached despite the careful advance planning outlined in the recruitment section of this chapter. In some of these areas, after repeatedly cancelling focus groups, interviews were set up in order to complete data collection.

Hierarchy within the group may take two different forms. Firstly, people attending the group may represent different hierarchical levels within a single organisation. This can lead to difficulties, as group members may feel inhibited by senior colleagues or senior staff may feel disinclined to speak openly in such a forum (Kean 2003). This issue was identified as a potential problem at the research design stage and Charge Nurses were deliberately excluded from the focus groups.

Secondly, hierarchies are likely to form within the focus group with different people taking on specific roles within even a short life group (Reed & Payton 1997). This may be particularly pronounced if there are pre-existing relationships within the group. While this could have been a particular difficulty in the sample groups, the recruitment of nurses from a number of wards may have alleviated the problem, as only a few instances of dominance were noted in the data.

There is some debate in the focus group literature about whether a focus group should comprise strangers or pre-existing acquaintance groups. This study made use of acquaintance groups for practical reasons. Kitzinger (1994) highlights the importance of common understandings and shared culture among previously acquainted groups in health care research. Common use of language and unspoken understandings allow the group to explore issues, challenge and support each participant's recollection of events. While this may allow the data generated by the group to be particularly insightful, the facilitator may have to work hard to understand fully the nuances of the discussion and may require to seek clarification from the group in order to interpret their meaning accurately. As a nurse researcher, I have some insight into the world of the general nurses. However, it became evident that this insight was limited to general medical settings and did not stretch into the mental health field. This is discussed further in the section dealing with the place of the researcher in chapter one.

Kitzinger (1994) suggests that an element of 'censure' caused by the group situation is inevitable in focus group data. This, she suggests, is not damaging to the integrity of the data as people do not operate within a social vacuum in the world outside the focus group. The group setting might stifle the will of individuals to step outside the group norm and to develop a line of thought that challenges a group of acquaintances (Barbour & Kitzinger 1999). This was evident in one focus group within this study. Albrecht et al. (1993) suggest that the social process of generating data within a group contributes to the validity of that data (Albrecht et al. 1993). However, there

are issues of coercion and conformity within a group which may open this claim to question. The artificial nature of the focus group may mean that data generated within that group can not be directly representative of the social world although the influence of that world is understandably great. The observation phase of this study was designed in order to address this concern and to allow the researcher some insight into the context of the nurses' workplace culture.

4.4.4 Facilitation

The role of the facilitator in focus group data collection is widely recognised to be both individually challenging and vitally important to the success of the group. There are a number of problems that a facilitator might encounter during the course of focus group research. These problems may arise during the group session itself or may emerge afterwards when the recorded sessions are replayed and analysed. When replaying the recordings of the focus groups in this project it, became clear that some further probing would have been beneficial in a number of areas and some ideas readily understood by me were not explored more fully with the nurses.

A topic guide was used to direct the focus groups. This included a number of general topic headings and some questions which could be used to shape the discussion. The guide was reviewed after each group and some additional points were added in order to explore, in subsequent groups, points emerging from earlier sessions.

Beginnings and endings are very important periods of the group as the facilitator sets the scene and subsequently concludes the group. The ground rules for the group must be clearly outlined at the beginning in order to safeguard group members and prepare an environment in which open discussion can take place (Stewart & Shamadasani 1990). This was an area of concern after the first focus group when it became evident that my own nerves made the opening of the focus group rather chaotic and confused. In order to improve this, a prepared opening statement was used in subsequent groups. Jowett (1996) also stresses the importance of a suitable ending,

where participants can leave the group feeling that the session is complete and that their contributions were valued and respected throughout the session. In most cases this was achieved, although one group did finish abruptly as pressures of time took over. These are aspects of the focus group sessions which could be improved in future projects.

4.4.5 Practicalities

The practicalities of running focus groups are covered in detail in a number of texts. A wealth of information can be found about where to hold a focus group, how to set up the room and how to physically set the scene in order that participants feel comfortable and inclined to participate. Macleod Clark et al. (1996) provide a useful summary of several of the practical aspects of running a focus group. Despite careful planning for many potential challenges, the eventual constraints of the clinical setting gave rise to a number of difficulties. Recruitment and subsequent attendance are issues which have been addressed in this chapter. A further challenge in running focus groups within hospitals was obtaining a suitable room. In order to ensure minimal travel time and maximise attendance, groups were run within the hospital. It was difficult to book rooms in advance; nurses had difficulty finding the room; locations were frequently in busy ward areas with potential for interruptions and distraction or just not conducive to meaningful and productive conversation. For example, one group was held in the board room which, while comfortable, made the atmosphere stiff and formal in a way which constrained conversation.

4.4.6 Interviews

Interviews have been used as a means of generating information since the time of the Egyptians (Fontana & Frey 1998). It is described by the same authors as being one of the most powerful and common ways of understanding other people. The interview has become one of the most important tools in social research. The original research design for this project involved only a small number of interviews. As the challenges

of holding focus groups in busy hospital wards became too great, the research design changed to incorporate more interviews and the place of the interview in this study became more important. Interviews can be carried out in a variety of ways and within a number of different epistemologies. In qualitative research most interviews help the researcher to interpret information and make sense of what is said (Warren 2002). Most interviews take place between two individuals, the researcher and the participant. Denzin and Lincoln highlight aspects of this relationship;

“The interview is a conversation, the art of asking questions and listening. It is not a neutral tool, for at least two people create the reality of the interview situation. In this situation answers are given. Thus the interview produces situated understandings grounded in specific interactional episodes (Denzin & Lincoln 2000b p633).”

The lack of neutrality highlighted by Denzin and Lincoln was evident in some of the data generated using this method of data collection. While I was aware of power dynamics within focus groups, the power dynamics of an interview setting were unfamiliar to me. It has been suggested that in some focus groups the facilitator may be seen to have power in the form of expert knowledge and status (Stewart & Shamadasani 1990) and that this may influence the dynamic of the group. This project highlighted that issue more clearly in the interviews where it became evident that some participants wanted to be seen to agree with me, regardless of the approach taken in questioning. This altered the dynamic of the interview and the resulting data.

Interviews may involve structured, unstructured or open ended questions (Fontana & Frey 2000). The interviews in this study were largely open-ended with several specific questions used to follow up or probe for more information on a specific topic. The topic guide for the focus groups was used initially with only a few amendments being made to suit the one to one situation. The Charge Nurses interviews also used this topic guide, with the addition of some questions specific to

their own clinical area. These questions were based on information gathered from nurses in focus groups or interviews.

The setting and timing for the interview was important in setting the tone for the interaction and putting participants at their ease. In order to maximise attendance and reduce time, interviews were completed in rooms on or close to the wards. In most cases, this was satisfactory as the room was familiar to participants and there were few interruptions. Interviews were held in the early afternoon to suit staffing levels. Attendance was not problematic as individual nurses could usually be released without stretching the staffing too much. The rapport developed in the interview is important to the quality of the data generated (Kvale 1996). The interviews were informal and allowed nurses to discuss both aspects of their work on the ward and their personal reflections on dementia. All interviews were recorded and transcribed, as outlined later in this chapter.

Interviewing nurses was an enjoyable part of the data collection and was generally less stressful than carrying out focus group sessions. However, some of the transcripts show a tendency for the interview to become less of a data gathering session and more therapeutic in tone. By this I mean, that in a few interviews I fell into the role of nurse, listening with empathy and failing to probe topics more fully if the nurse became uncomfortable. While the rapport of an interview is important and people should be put at their ease, it is also necessary to generate high quality data through probing and far reaching questions. At times, my inexperience in this regard has been evident and the interactions have slipped back towards the more therapeutic encounter of a nurse-patient interaction.

4.4.7 Observation

“Observation is one of the oldest methods of data collection (Sarantakos 1998 p219).”

Originating in the fields of social anthropology and ethnography, observational techniques are now employed throughout the social sciences. It is a technique which, unlike the other methods in this study, is indirect and collects data about which the participant may know or understand little. On many occasions during the observation stage of the study I was asked what I was actually looking for. The nurses who questioned me had participated in other phases of the study and understood the project yet they found it difficult to see what could be gained from observing them interacting with dementia patients. By its nature, observational research can vary considerably between different researchers and throughout the different stages of a single project (Adler & Adler 1998).

One of the first decisions to make about observation regards the level of participation of the researcher in the field. Participant observation would require the researcher to be part of the group being studied; for example, working as a nurse on a ward while observing practice. Non-participant observation means that the observer stays outside of the group, perhaps observing from a hidden location or at least remaining separate from the immediate area being studied (Sarantakos 1998). As a nurse observing nursing practice I fell somewhere between these realms! I was neither part of the group being studied nor totally separate from it. The decision to be a non-participant observer was made for four reasons; firstly, the work of Bourdieu which informs this study suggests that an outsider would fail to be truly part of the study field while carrying out a short period of observation. Bourdieu's view of observation generally was not wholeheartedly supportive. However, through reflexivity, he suggests it may be possible to observe as a non-participant, making clear the researcher's own position as distinct from the study group while writing the findings. Secondly, access

and ethical approval for participant observation are relatively complex and difficult to arrange in Scotland. Thirdly, the observational phase of this study was intended to be a relatively short adjunct to the other data collection methods and was designed to happen after the focus group or interview sessions. Participant observation would not have been possible having spoken to the nurses prior to the observation period. Finally, as an individual, the observation was the method of data collection that I felt least happy with. This discomfort would have been compounded by participating as a nurse on the ward and engaging in 'role-pretence' during the observation period (Gold 1958).

Observation was made of the wards and interactions between nurses and patients. While my presence as a researcher almost certainly altered some of these interactions, this impact reduced as the nurses got used to my being in the ward. Some notes were made while in the ward, especially during quiet periods. At other times, I made oral notes into a dictaphone which I later transcribed into field notes. Observation took place in sessions of two or three hours in most clinical areas. I altered the times of my visits and visited both day and night shifts. This was particularly important, as those with dementia often wander during hours of darkness and many meaningful interactions between nurse and patient took place on the night shift when other patients were asleep. I continued to visit wards until I felt that I had answered all my own questions or had seen most regular aspects of care. In some settings, it took me longer to become familiar with the setting than in others. For example, I spent much longer periods in mental health continuing care wards where I was unfamiliar with the approaches taken on the ward, the culture of mental health nursing and the structures of the environment. Acute medical areas became quickly familiar as I understood many of the unspoken aspects of those clinical areas from my own past work experience. Using observation to understand structural and cultural aspects of the clinical settings was a primary aim in observing practice. This fits comfortably with my own experiences as a nurse and also with Bourdieu's theories. Furthermore, the use of observational techniques to achieve this is supported by Adler and Adler (1998). They report on the work of Georg Simmel who

studied social order through his observation of structures and relationships being played out in the social world. Observing, from his personal view point, the relationships between individuals, structure and institutions, allowed him a unique insight into society. This insight was used in his writing where he recognised his own marginal position as a Jewish scholar and reflected on his observations from this vantage point (Adler & Adler 1998). My own position as a nurse researcher within two different nursing environments could be seen as a rather simplistic version of Simmel's position. My own observations, together with my reflections about both my nursing and personal backgrounds, should inform the discussion of the data which is laid out in the following chapters while also remaining true to Pierre Bourdieu's reflexive sociological project.

4.5 Generating and Organising Data

4.5.1 Recording

All focus groups were recorded using both a cassette recorder and a mini-disk recorder. A flat-bed microphone was placed in the centre of the table in order to pick up voices from around the room. All participants were explicitly told about the recording, both at the time of giving consent to participate, and at the start of the data collection session. The mini-disk recordings provided a back-up in case of cassette failure. Participants were reassured about confidentiality and cassettes were all stored in a locked file box. Audio cassette recording has the advantage of recording the entire group and avoiding the researcher's selective memory of events which threatens the quality of the data (Bloor et al. 2001; Krueger 1993). It also leaves the researcher free to play a part in the group (Lofland & Lofland 1995) or facilitate effectively. In addition to the audio recording, notes were made immediately after the focus group in order to record any aspects of non-verbal communication which had been notable during the session. This was completed while the researcher remained in the room where the focus group had taken place, as this proved to be a useful memory aid in considering the group. Interviews were recorded in the same way, using the same equipment.

4.5.2 Transcribing

The process of transcribing data from audio tape has been described as an important part of data analysis;

“the preparation of a transcript from an audio – or video tape is a theoretically saturated activity. Where there is more than one researcher, debate about what you are seeing and hearing is never just about collating data – it is a data analysis (Silverman 2000 p830).”

With this in mind, I started to transcribe the data myself. This was a time consuming task but had the great advantage of allowing me to consider the recording, transcript and field notes together, reliving aspects of the focus groups and deriving meaningful benefit in this process. The words spoken were carefully transcribed and some aspects of the non-verbal communication were added in the margin at the places where they occurred. Detail, such as audible breathing, can be recorded in transcription (Kowal & O'Connell 2004), however, this detail was not noted unless it related to non-verbal communication. For example, an exasperated sigh was recorded, as it made unspoken comment on the contribution of another group member. The time taken to transcribe the material was substantial. Blaikie suggests;

“it has been estimated that an experienced transcriber, with clear recordings, will take at least three hours to do one hour of recorded interview (Blaikie 2000 p31).”

As an amateur dealing with multiple recorded voices, this estimate could easily be doubled. With maternity leave looming and pressure of time, a secretary who specialises in this type of work, was employed to complete the transcription. The interviews were nearly all transcribed by the same secretary who completed the task with great accuracy, allowing me more time to listen to the recordings and immerse myself in the data.

4.5.3 Organising Data

The large quantities of data generated by the focus groups, interviews and observation needed to be managed and organised in some way and computer programmes were recommended for this purpose. Advantages of computer programmes for organising data and assisting with analysis are reported to include the speed of managing large volumes of material, improvements in rigour, facilitation of team research and improvements in sampling and theory development (Seale 2000). I was encouraged by these advantages and started to use *Ethnograph* to assist with the storage and retrieval of data. I used this system to explore the pilot study data which will be discussed in the following section. There is much debate in the literature and among the research community as to the utility of software for data analysis. I must confess that my decision to leave the software behind and analyse the study data manually had less to do with the academic debates and more to do with practicality. My own computer skills may have been lacking and my ability to manipulate data effectively on the computer was certainly impaired. As a result, the study data were analysed using a traditional and, doubtless inefficient, cut and paste system involving a series of ring binders and a great deal of floor space!

4.6 Pilot Study

During the lengthy period between the summer of 2003 and the start of data collection in early 2004 some time was spent developing data collection techniques through a pilot study. The pilot data had to come from individuals who were volunteers and not through the NHS where ethical approval and access permissions were being sought. At the conception of the pilot study, it was anticipated that only a short time would be available before data collection proper began. No plans were made to analyse the data fully but, rather, to practise previously untried data collection skills.

Two pilot focus groups were run. The participants were healthcare workers from a variety of background who were all studying for a healthcare qualification at the local college and who saw the focus group as an opportunity to talk about a topic which was relevant to their own studies and assisted my development. No financial reward was offered. The group received refreshments and time was spent discussing aspects of their education and their course in the period immediately after the focus groups. I am very grateful to these individuals who gave willingly of their time in order to help me develop my skills.

Two different sets of recording equipment were used in order to see which offered the better sound quality. The topic guide prepared for the hospital focus groups was used although some points were omitted as they were considered to be more relevant to registered nurses. The focus groups took around 45 minutes and covered a wide range of issues. One of the most striking aspects of the data from these groups was the personal nature of the material. As volunteers, these individuals may have chosen to take part because they wanted to discuss personal experiences of dementia or, perhaps, they did not have the professional contact with dementia patients that the subsequent study groups had. However, these groups highlighted the potential personal cost of taking part in this research and this led to a reconsideration of both the topic guide and the arrangements for supporting nurses who took part.

Both focus groups were transcribed and the data were prepared for *Ethnograph* where they were coded, using provisional codes which emerged from the data. This simple approach offered important opportunities to learn about the computer package and to develop codes from the data. However, it also highlighted the need to find a more substantive method of coding which would be less haphazard and reflect more of the structural and relational aspects of the study settings. The data from the pilot study were never intended for use in the main study and, while all participants had given their consent it seemed to overstep that consent to use the material along with the study data. However, the pilot study was invaluable in developing skills and

pointing to areas where further theoretical development was necessary prior to the study proper. The relationship between a pilot study and main study is poorly covered in the literature (Gardner et al. 2003). Gardner et al. suggest that the outcomes of a pilot study should be process related rather than research question related, identifying methodological weaknesses and problems with techniques or instruments which may detract from the success of the main study. The pilot study in this project fulfilled these aims and was an invaluable stage in the research development process.

4.7 Data Analysis

The process of starting data analysis took a long time! The questions of where and how to begin were challenging and the volume of data generated through the focus groups only served to make the process of beginning more difficult. Wolcott suggests describing the data as a first stage in analysis (Wolcott 1994). Descriptive accounts of the first two focus groups, however, were uninspiring. Using the analytical headings of Schatzman and Strauss (1973) improved the writing as observations, theoretical points and methodological issues were highlighted. However, neither approach moved the analysis forward significantly.

Bourdieu's writing did not help the early analysis endeavours as my obsession with 'coding' the data served only to distort an overall view of the study field. Bourdieu suggests that the field must be the primary focus of study rather than the individual actions within that field. Therefore, the process of 'coding' which had been the focus of taught data analysis courses and many texts was not a useful starting point in this project. However, the early time spent transcribing, reading, re-reading and cutting pieces of data was hugely beneficial to the overall analysis project as I familiarised myself fully with the material. Two further points emerged from this early analysis work. Firstly, the data told nurses' stories and represented their view of their own and their patients' experiences. Relationships between staff members, nurses and

patients, ward structures, obligations and roles were all part of the nurses' stories. The initial coding process did not take account of these relationships and was, therefore, lacking in depth. Secondly, the coding showed the importance of my own position within the study field. This was outlined in chapter three when discussing reflexivity but became particularly clear in this period of analysis when my rather naïve approach meant that my own views were clearly displayed in the choice of codes and use of the data. These two issues are discussed more fully in the coming sections.

4.7.1 Telling Stories

“Sociology is bound up both with obtaining stories and telling stories ... (...) ... everywhere we go, we are charged with telling stories and making meaning ... the social order heaves as a vast negotiated web of dialogue and conversation. So-called social science is not cut off from this activity but is itself very much part of it: it is simply an occasion of more systematic reflection and story telling upon the world (Plummer 1995 pp19-20).”

The stories that are told and understood are part of the social world and reflect the position within that world of both the person creating and receiving the story. The audience will, for example, reflect the way that a story is told, as the teller is aware of how they would like to portray themselves and what the audience expects to hear. These social processes involved with the production and reception of stories are influential. It became clear during the early analysis phase that this was an important aspect of the data and fitted clearly with Bourdieu's ideas about the diverse fields of information production and reception. A method of incorporating these aspects of the data into analysis had to be considered.

4.7.2 Self and Other

The position of myself as researcher, nurse and family member of someone living with dementia came into sharp focus during this tentative early analysis. A more detailed account of this complex personal position is given in earlier chapters. However, it is relevant also to the analysis of the data. The early analysis showed how much my own experiences influenced my analysis and my personal priorities and opinions were reflected in much of the rather naïve analysis of the data. Bourdieu stresses the importance of reflexivity and my experience of early analysis highlighted how important that would be in this project.

4.7.3 Life Changes

The analysis phase of this project also coincided with some important personal changes in my life and these changes influenced the analysis process. My son was born after analysis of the pilot data but prior to my settling on a strategy for the analysis of the study data. This event enriched my life in countless ways but also changed my focus. After a period of maternity leave, I returned as a part time student to continue with analysis. The early months were characterised by a fragmented approach while I juggled my new roles and study demands. The analysis reflects this rather tumultuous period with a number of avenues being explored before a clear analysis strategy was reached. These wrong turnings on the road towards analysis were frustrating but added greatly to my understanding of the data and how best to approach the analysis of the material.

4.7.4 Bourdieu

Bourdieu's work does not lay out a plan for data analysis but does outline two significant guiding principles and three clear steps towards analysis. Firstly, researchers should be reflexive in their approach and, secondly, the field should be the focus of analysis. These principles sound simple but were almost forgotten in the initial data analysis. Reflection has developed throughout the analysis and has

involved considering and reconsidering my own opinions and positions in the light of material emerging from the data and changing personal circumstances. Secondly, the focus on field was clear from the outset but the means of achieving this focus was obscured. Using the three analysis steps outlined by Jenkins in his commentary to Bourdieu's work has assisted greatly in bringing the field into focus (Jenkins 2002). These three steps, discussed in section 3.6.2, are outlined again below;

- Consider the relationship of the field in question to the field of power.
- Within the field in question construct a social topology of the positions making up the field.
- Analyse the habitus of the individual actors and the strategies or trajectories produced by interaction of habitus with the constraints of the field.

(Jenkins 2002 p86)

The first two steps culminated in the production and later revisions of the diagrams shown in appendices one, two, and three and discussed in detail in the previous chapter. This process of development represented the most significant part of the data analysis process. Data which had been 'coded' during early attempts at analysis were re-visited during this period. Relationships between each individual nurse and the structures of the workplace, interactions with patients and feelings about dementia were explored in detail. All of the previously coded data were re-labelled in terms of relationships between the individuals and the wider field or context. That is to say, each individual action or comment was considered against the backdrop of the study field. A list of relationships was formed and these common relationships became apparent. For example, nurses related to the patients in their care, the layout of their ward area, the diagnosis of dementia, their work colleagues and countless other relationship examples. The diagrams included in appendices one, two and three show

how the relationships come together to make the field of inpatient dementia care. After the initial outline of the field became clear, further details were added in order to explore the nature of the field in more detail. For example, power distribution within the field was considered in detail and became a useful way of exploring and characterising relationships within the field. Social norms and expectations were also made explicit in order to make clear the influences on nurses in their conceptualisation.

Developing these diagrams allowed the field to become the true focus of the analysis and allowed relationships within that field to be made explicit. These relationships became the template for analysis of the data and each transcript was reviewed with these diagrams and relationships in mind. This strategy took a long time to develop but, within a short period, it was clear that this approach allowed the data to tell a story and reflect some of the dynamics of the field. The third stage required the analysis of habitus. Cultures and philosophies employed in the clinical settings were examined and the attitudes and demeanour of nurses in their approaches to patients observed. The nurses' views of dementia were assessed against the backdrop of the social world in which their interactions take place. Finally, the analysis of habitus culminated in my reflecting on the care given by the nurses and my own personal and professional views. This analysis was the part of the project which I did not know how to approach. However, through detailed analysis of the data in my search for answers to the first research question, aspects of habitus began to emerge. The distance and time away from the data afforded by two maternity breaks also helped this process. While these breaks cost time in reacquainting myself with the data and with the analysis process, the gaps have been hugely beneficial in bringing aspects of habitus into focus.

4.8 Writing

Using Pierre Bourdieu's writing as a theoretical framework for this study was hugely significant during the analysis process. The diagrams included in appendices one, two and three, provided a helpful framework, as outlined in a previous section. However, Bourdieu also influenced the writing of this thesis. Bourdieu's reflexive sociological approach stresses the need for transparency, both in the analysis and writing of academic work. Differences are recognised between the field of production of information and the field of reception. That is to say that the intentions, motivations and influences of the author should be made explicit in order that the reader can evaluate the information presented. Furthermore, the author must be aware that the receiver of the information will read the information from a position which differs from the position of the author as their influences and backgrounds differ. With these aspects in mind, the thesis returns often to the personal position of the researcher and reflective remarks and accounts are presented alongside the data from nurses. A personal view of dementia is included beside the literature which guides the study and further personal reflections are included in discussion at the conclusion of the thesis. These inclusions seek to address the reflexive requirements of Bourdieu's work, while differentiating clearly between personal reflections and data generated by the nurses.

Further to the reflexivity required by the theoretical approach, the approach also helped with the organisation of the thesis more generally, as four key ways of conceptualising dementia emerged from analysis of the field. Data are presented in four chapters which reflect these four key conceptualisations and literature, which is relevant to each of these themes, is included alongside the data in order to clearly link theory, data and practice.

4.9 Quality

Ensuring the quality of a qualitative study is an important and much debated subject. Validity and reliability are understood to be indicators of quality. However, these measures come from the positivist tradition (Bailey 1997) and are not easily

transferable to this study. Kitto et al. set out criteria for assessing qualitative research submitted to a journal for publication (Kitto et al. 2008). These criteria include procedural rigour, interpreting data in the light of existing theories, providing a conceptual discussion of the data, reflexivity and evaluative rigour and linking findings to policy, practice and current knowledge. However, recent debate in the literature has raged around the question of whether or not qualitative studies can be judged by criteria at all, as qualitative studies are not all one homogenous group and do not follow a common approach (Rolfe 2006). This argument leads to discussion of individual studies requiring quality measures which are particular to the study in question and take account of the methods and approach used. Rolfe (2006) concludes;

“...I have argued here that the quality of a research study is not only *revealed* in the writing up of that research, but also that it somehow *resides* in the research report and is therefore, in Sandelowski’s terminology, subject to the wide judgement and keen insight of the reader Such judgements about the quality of research studies demand that the reader has some practical expertise in the research process, and that these appraisals cannot be made by novice researchers merely by following a set of critical guidelines or criteria (p309)”

Rolfe’s assertions about the lack of homogeneity between qualitative studies are both interesting and insightful, pointing to challenges in determining the quality of non-quantitative research through the use of quality criteria. However, his conclusions that quality resides in the written research report does not sit comfortably with Pierre Bourdieu’s remarks about the field of academic production differing from the field of reception. Furthermore, the need to have practical research experience in order to interpret the quality of a research report limits significantly the use of such reports and calls into question the potential for presentation of quality research by those undertaking research training.

In a response to Rolfe's paper, Sam Porter accepts his premise that qualitative research can not be judged as a single entity and suggests the use of realist strategies for the determination of quality (Porter 2007). These strategies build on the assumption that there may be a number of different explanations for a single phenomenon (Hammersley 2004) and explanations will be socially produced against the backdrop of the relevant power dynamics and social structures (Bhaskar 1989). While it is necessary to ensure that the researcher's representation of the phenomenon or experience being researched is accurate, the realist approach to quality allows other explanations to hold equal weight, as individual influences alter the research data and outcomes. This approach sits comfortably with the work of Pierre Bourdieu and the concept of 'plausible stories' as described by Melia (1997). Procedural transparency is an important element of any research project but Melia argues that finding plausible stories in the data should be the primary outcome of a study. These stories must convince relevant groups or individuals in order to ensure that they do not simply represent the preconceived ideas of the researcher (Melia 1997).

In this study, as the researcher, I did start the study with ideas from both personal experience and professional practice. In order to ensure that the stories found in the data were plausible, it was considered important to return to the study areas to discuss the findings with nurses who had participated in the data collection. However, the practicalities of maternity breaks, staff turnover over the extended period of time and expiry of the access permissions, all conspired to make this impossible. This was a disappointment to me as I had hoped to take the project 'full circle', a strategy which had potential benefits both for the nurses themselves and for this project. A number of the Charge Nurses still remained in post towards the end of analysis and I visited four of these individuals and spoke to another over the telephone in order to discuss the findings. This was less than satisfactory but did go some way towards ensuring that the ideas emerging from the study were fed back to the clinical areas and the wards continued to have some involvement in the project.

Mixing methods of data collection also raises issues of quality. This study used focus groups, interviews and observation. In order to assimilate the data, data from focus groups and interviews were analysed together. Observation data formed a backdrop to this process, as images from observation came back to me during the analysis of the spoken data. However, the observation notes were used, firstly, to draw up the diagrams which formed the basis of the early analysis. These diagrams have been discussed in a previous chapter and are included in the appendices. Secondly, the observational notes were used to familiarise myself with the study areas and to reacquaint myself with these areas following maternity breaks. All data were analysed using Bourdieu's framework which pulled the data together, despite the different characters of the data themselves.

The reflexive approach required by the use of Bourdieu's theories to shape this project has potential benefits for research quality. Exploring subjective aspects of the research process is recognised as an important step in qualitative research (Bradbury-Jones 2007). The reflections included throughout this thesis make subjective details explicit and allow taken for granted assumptions to be made clear throughout the research process. Current literature demonstrates a wide ranging debate about the ways to demonstrate rigour in qualitative research. This thesis adopts a pluralistic approach to quality (Tobin & Begley 2004) which includes detailed accounts of procedures, adopting best practice with individual data collection methods, transparent analysis using diagrams in order to make relationships clear and integrating reflexive accounts throughout the writing. These methods, along with the approach of Pierre Bourdieu, hold the thesis together and allow plausible stories to emerge from the data.

4.9.1 Limitations

Using a reflexive sociological approach has required analysis of limitations and weaknesses at each stage of this work. As a result, limitations are noted, as they

emerge, in the course of the thesis. For example, data collection could have been improved by more detailed probing during interviews and more explicit questioning in the early focus groups. These are limitations resulting from inexperience and the techniques improved during the data collection phase of the study. The two maternity breaks made it impossible to arrange feedback sessions in the clinical areas as discussed in a previous section. Despite efforts being made to discuss the findings with Charge Nurses in the participating hospitals, the omission of feedback sessions is also recognised as a weakness in this work.

Finally, the sample group of contributing nurses could also be seen to limit this study. Nurses were drawn from acute medical and psychiatric areas, assessment and rehabilitation units and mental health continuing care areas as outlined in sections 4.1.2 and 4.3. Visits to general medical run continuing care wards showed few people living with dementia resident there. Those who did have dementia also had complex medical needs which were the focus of the nursing care and the majority were bed bound. These clinical areas were, therefore, omitted from the study. As a result, the sample group comprises a number of mental health nurses from continuing care environments and very few general nurses with this kind of care experience. While good reasons existed for choosing not to collect data from general continuing care nurses, their contribution could have provided a more balanced profile in the sample group.

4.10 Conclusion

This chapter has discussed the ways in which this study was conducted. Starting with the early research ideas and the development of research questions the chapter went on to outline the procedures undertaken in order to gain access to clinical areas and recruit participants. Some of the challenges encountered during the project were discussed. Methods of data collections and analysis were considered. My own position as a nurse and a researcher was discussed, together with the use of Pierre

Bourdieu's work in shaping this thesis. Finally, issues relating to the writing of the thesis and ensuring quality in qualitative research work were discussed.

CHAPTER FIVE

DEMENTIA: A DISEASE

5.1 Introduction

The concept of disease enjoys a privileged position within the study field and within the wider social world. As a concept, it is influential in determining the work of the field of inpatient dementia care and in shaping relationships and actions within that field. In line with Bourdieu's assertion that the field should be the primary context for the analysis of social situations, this chapter begins by considering the concept of disease within the context of the study field. Using the topology outlined in Chapter three and included in Appendix one as the basis for the analysis, this chapter seeks to examine the concept of disease in terms of the relationships and actions which it influences, the capital exchanged and the resulting cultural influences on the study field. This analysis of disease within the context of inpatient dementia care will then be used to interrogate the data and explore the nurses' conceptualisation of dementia as a disease process. Data will be presented to demonstrate ways in which the concept of disease shapes nurses' understandings of dementia and how this relates to the study field. Data on diagnosis, treatment and the progression of disease will be presented. Examples of ways in which the nurses' understandings relate to their care and care planning will also be explored and presented in this chapter. Finally, conclusions will be offered highlighting the relationships between the dynamics of the field and the concept of disease and demonstrating how nurses' conceptualisations of dementia relate to their practice.

5.2 Concept of Disease in Context

A disease label can have far reaching implications both within the field of inpatient dementia care and within the wider social world. It legitimises patterns of behaviour and shapes the way in which people react to each other and the disease label itself. For example, a diagnosis may excuse an individual from work or personal obligations. It may allow an individual to choose or decline certain foods, move around in unusual ways or be inattentive during conversation. The label of a 'disease', even as simple as the common cold, can have far reaching effects on expectations and, subsequently, on actions and reactions (Gerhardt 1989; Parsons 1951).

Disease is often considered to be a process whereby a collection of symptoms combine to produce a recognisable effect which can be labelled through diagnostic procedures. From early beginnings as *dis-ease*, meaning discomfort or distress in a general sense, the word has taken on more medical connotations in modern English usage. The Oxford English Dictionary charts this move through the definition outlined below;

- a) A cause of discomfort or distress; a trouble, an annoyance, a grievance
- b) A condition of the body, or of some part or organ of the body, in which its functions are disturbed or deranged; a morbid physical condition; 'a departure from the state of health, especially when caused by structural change'
- c) The condition of being (more or less seriously) out of health; illness, sickness. An individual case or instance of such a condition; an illness, ailment, malady, disorder.
- d) Any one of the various kinds of such conditions; a species of disorder or ailment, exhibiting special symptoms or affecting a special organ.

(Oxford English Dictionary Online accessed 17/09/08)

5.2.1 The Social World

Disease processes proceed from diagnosis to treatment with the aim of reaching a cure. In the case of a simple cold this process is largely completed informally without the need for formal diagnosis or complicated medical treatment. Lay people reach their own diagnoses and use their own strategies to alleviate symptoms before the body reaches a state of recovery. This process of diagnosis, treatment and cure is, therefore, part of the social world in which we live. It is a process borne of the body's own natural ability to fight disease and recover health. Furthermore, the societal expectations enshrined in Parsons' Sick Role (1951) provide a backdrop for thinking about disease and recovery, as an individual is expected to strive to regain health and thus recover productivity. This theory will be discussed further in a subsequent section. The development of medicine and advancing techniques have led to the ability to diagnose and fight ever more complicated diseases and have raised expectations of cure amongst the general public. These expectations are socially situated and are influenced by many of the factors which influence the social world more generally. For example, geography is a key determinant of expectation, as different countries across the world enjoy different levels of healthcare and life expectancy. Even within the U.K. there are wide variations in health expectation based on geography and social class among other factors.

Diagram three, outlined in chapter three (Appendix three), shows the influences on the social world which emerged from analysis of the study data. These eight aspects of social life act as background structures which serve, both as a framework on which to build our society and as factors which influence and demonstrate differences within that society. The simple grid design of the diagram does not seek to extrapolate the complex relationships between these macro structures but, rather, to serve as a reminder of the complex web woven through the fabric of the social world. As such, these factors can be used to consider the concept of disease and to highlight some of the many factors which may influence individual expectations of disease. For example, understandings and expectations of disease may vary between ethnic groups. Specific diagnoses may be more common in some social groups than

others while the acceptability of treatments may vary with regard to religious belief. Educational background may influence understanding of disease or treatment as might media portrayal of disease processes. Disease, therefore, is a term which is broadly understood within society but is subject to a great deal of individual interpretation. While the macro structures of the society in which we live contribute to this variation, personal experiences and individual factors also play key roles.

5.2.2 Medical / Psychiatric Practitioners

Diagram two (Appendix two) was also outlined in chapter three and lays out some of the complex power dynamics within the study field. This diagram can be used as a starting point for the consideration of the importance of disease within the context of the field. The place of disease in society at large has already been outlined. A disease label has the power to excuse individuals from responsibilities and influence the interactions of individuals. Parsons' Sick Role exempts a patient from work and family commitments during the course of ill health and affords the right to support without blame to the individual during that period (Parsons 1951). However, in return, the patient must strive for recovery and seek the expert help of a doctor or psychiatrist in order to recover health. Parsons' theory grants the practitioner considerable power. The doctor has intimate knowledge of the patient, quite unlike the information exchange which could be expected within a relationship between two equal individuals. This power imbalance shapes the relationship. Furthermore, the doctor has the power to influence both the life and productivity of the individual patient and, therefore, influence the exchange of capital in society at large.

The power to bestow a disease label is, therefore, highly significant and is a position held in high esteem by society at large. The education, knowledge and experience of the medical or psychiatric practitioner contribute to this esteem and the power of the doctor both within the field of hospital care and also, significantly, in society at large (Goodrich & Wang 1999). This power can be seen in the data and will be highlighted

in the data presented later in this chapter. The role of the doctor or psychiatrist in diagnosis and some of the anomalies raised by dementia specifically will also be discussed later in the chapter. However, the importance of the power wielded by doctors and psychiatrists making diagnoses is significant in shaping the overall dynamic of the study field and relates strongly to the habitus underlying the relationships within the field. This power dynamic can be seen clearly by the demeanour of some patients towards nurses and doctors, aspects of ward organisation and the over-riding authority of the doctor in bestowing a disease label.

While power may have been undermined by much publicised scandals involving doctors (Sheach Leith 2007) and by societal change more generally, the traditional power dynamics remain in many areas and, specifically in the care of older people. Observations made during this study suggest that older people hold a traditional respect for doctors which shapes their behaviour and manner of interaction with medical staff. This was evident in the deferential way in which many patients spoke to medical and psychiatric staff. They were unquestioning of doctors' opinions in a way which differed from their reaction to nurses and family members. The power of medical and psychiatric practitioners within the field of study is clear and relates to their role in determining and distributing disease labels. The power differential between patient and doctor is perhaps most evident in the care of older people, many of whom adhere to traditional views of the power dynamics within the relationship (Frey 1999).

5.2.3 Nurse

The focus of this study is the nurse who has a rather ambiguous role to play in terms of disease and disease labels. The nurse has a greater understanding of disease than members of the general population. He/she is educated in respect of disease processes, their effects and treatments. However, in most cases, the nurse does not have the power to assign a disease label or confer a formal diagnosis which then

remains with the patient over the course of their life. For example, a nurse may care for a patient who has symptoms suggestive of a condition. While the nurse may assess the patient, perhaps carry out diagnostic tests and form an opinion about the diagnosis, it is rarely the nurse who formally makes the diagnosis. This can raise difficulties in practice where it may be difficult to define and document the specific role of the nurse in diagnosis. Castner (2008) highlights this with reference to nurses working in accident and emergency departments (emergency rooms) in the USA;

“... when a patient arrives with a compromised airway, the expert emergency nurse autonomously initiates positioning, suction, and administration of oxygen, prepares equipment for intubation, secures intravenous line access, and may request an order to ready a sedative and paralytic before the physician reaches the bedside. Teasing out only exclusive nursing diagnosis and functions at the point of care distracts from the important collaborative role. (Castner 2008 p34)”

While the realities of accident and emergency nursing are far removed from care of older people, the anomalies regarding nursing diagnosis remain. Nurses do assess patients and may make ‘nursing diagnoses’ (Herdman 2008) which may be influential in determining care. In a recent debate about proposed changes to the definition of nursing diagnosis, Herdman outlines the current definition which dates from 1990.

“A nursing diagnosis is a clinical judgement about individual, family or community responses to actual or potential health problems/life processes. A nursing diagnosis provides the basis for selection of nursing interventions to achieve outcomes for which the nurse is accountable (Herdman 2008 p4).”

This definition and the example given by Castner demonstrate that nursing diagnoses are an important part of patient care. However, these diagnoses do not result in the

granting of a disease label but, rather, relate to the specific recognition of symptoms, behaviours or effects of ill health. While these nursing diagnoses are crucially important to the care of patients, they are not synonymous with the diagnosis of a medical or psychiatric practitioner. The proposed changes to this definition of a nursing diagnosis stress the importance of multidisciplinary collaboration in meeting the needs identified by nurses. This proposed change takes account of changes in the structure and organisation of health care services but does not change the nature of the nursing diagnosis itself. The structures and power dynamics of the study field dictate that the diagnosis recognised in the wider social context, in most instances, is that of the medical or psychiatric practitioner and not the nurse.

Nurses are educated within a medical model of care. Indeed the dominance of medical knowledge in defining and treating illness has been highlighted in sociological writing for many years (Coombs & Ersser 2008; Friedson 1970; Friedson 1988; Friedson 1994). Disease is central to this paradigm and nurses are both educated and socialised into making clear connections between diagnosis, treatment and cure. This culture is all pervading and forms part of the nurse's view of both patients and disease. Some would argue that the medical model even influences lay perspectives of health and illness as the power of this model is so great (Stickley & Timmons 2007). Even in areas where cure is not central to the care, for example, palliative care, nurses aim to treat symptoms and improve quality of life through restricting the effects of the disease. The medical model forms a backdrop to the field of this study and influences the nurses in their work and my own position as a nurse researcher.

The educational background of the nurses and the centrality of disease within the care settings make it unsurprising that many nurses conceptualise dementia in terms of disease. The disease label serves a number of purposes and contributes greatly to the nurses' approach to the patients and their care. This is true of study settings within mental health hospitals, as well as within medical settings, and despite there

being significant differences between the settings, the medical model of care is an influential feature of the field as a whole.

The data show that the nurses' ideas about disease focus on diagnosis, treatment, course of disease and cure. These broad headings relate strongly to the medical model of care. Each of these topics were discussed by the nurses during data collection and were important aspects of the nurses' overall conceptualisation of dementia in terms of disease.

5.2.4 Use of Language Within the Field

Bourdieu stresses the importance of language as outlined in chapter three. He suggests that language is a powerful tool which can be used by one group to dominate another group within a field. Jargon and use of medical terminology could be seen as examples of this within a healthcare setting where such language can distance a doctor or nurse from his/her patient. Furthermore, language can be used to demonstrate belonging to a particular group through the use of phrases which have particular meaning within that group. This could also be seen within a healthcare context where phrases can be used between staff as a short-hand for much more detailed exchanges of information. Language is discussed more expansively in chapter three but is a significant part of the context of the data in this chapter. Throughout the presentation of data which follows, it is necessary to assess the language used by the nurses and the motivations and meanings held within their remarks. Bourdieu's insights into the complexities of language use allow the data to be examined in greater detail than might otherwise be possible. This analysis of language permits useful insights and promotes further discussion of the nurses' conceptualisation of dementia as disease.

5.3 Presenting the Data

The early part of this chapter has provided context for the data from nurses who conceptualise dementia in terms of disease. These data are presented in the pages which follow. The medical model which determined much of the thinking in the clinical areas is reflected in the order of the data presented. Firstly, data relating to nurses' knowledge of diagnosis, the practical utility of specific diagnostic labels and the process of obtaining a diagnosis are presented. Thereafter, data which address progression and treatment of dementia are presented followed by nurses' comparisons between dementia and what is referred to as 'normal ageing'. Finally, examples of the use of this conceptual framework in practice are given. Conclusions and reflections about the nurses' conceptualisations of dementia as disease are offered.

5.4 Dementia as Disease – Diagnosis

The diagnosis of dementia is a complex and much debated topic. As outlined in chapter two, dementia is an umbrella term describing the symptoms evident in a number of individual conditions. However, the diagnosis of specific conditions can be challenging, with some diagnoses being confirmed only at autopsy. The difficulties surrounding diagnosis may contribute to some of the issues raised by the nurses in this area. However, the complexity of the topic did not dissuade nurses from discussing diagnosis and using it to shape their overall view of dementia. The nurses demonstrated a range of knowledge about diagnosis in dementia care and this shaped much of the data on this topic. The practical utility of the diagnosis, the process of obtaining a diagnosis and finally the status of diagnosis within the field were all themes of the data.

5.4.1 Knowledge

The study nurses lacked detailed knowledge of the specific diagnoses, indeed many could not name more than one or two during conversation. This startling lack of

knowledge must reflect both the educational preparation of pre-registration nurses and the ongoing education of practising nurses. The data do not show the gaps in the nurses' knowledge very clearly, despite impressions gained from the data collection process. Remarks made during the data collection showed some gaps but field notes also noted some of the glances between colleagues which said so much about the nurses' uncertainty about this topic. For example, the following extract from the first focus group is accompanied by a field note extract.

Helen: ... I mean, we have, we have people in for various reasons who are confused, maybe for acute reasons, em, infections ... we always know the ones who are, who have actually been diagnosed as having some form of dementia whether it's Alzheimer's or (pause) some, some other form (RN – Registered Nurse).

Some panic on the faces of the nurses as 'Helen' looked round for colleagues' assistance when listing the types of dementia. Two people looked away from her while another shrugged, glancing apologetically at me. Some discomfort as the nurses obviously thought that I expected them to know some different types.

During the observation phase of the study there were a number of nurses who made remarks to me about patients having "dementia or Alzheimer's" which once again demonstrated their lack of knowledge about the specific diagnoses and the general umbrella term.

There was a noticeable difference between the knowledge of those from mental health backgrounds and those in general areas with the mental health nurses demonstrating a greater knowledge of the specific types of dementia than their general nursing colleagues. They also recognised the value of knowing the specific disease types as they could relate these labels more clearly to sets of effects. This was a point noted during an interview with Steven;

SJR: But what other things would you say are specific to your mental health expertise?

Steven: Yeah. The other thing that's kind of specific to mental health expertise is probably the understanding of dementia and the identifying different types of dementia and different kinds of illnesses and then caring and treating for them accordingly (MH – Mental Health Nurse).

None of the mental health nurses who participated in the study failed to realise that there are different types of dementing illness. This is a clear difference between the two groups of nurses and may relate primarily to the differences in education. However, there are also other differences which may contribute to this more detail conscious approach to the specifics of dementia diagnosis. For example, the mental health teams knew the specific diagnoses of their patients and those patients were admitted to the care setting because of their dementia and its effects. In the general medical areas, dementia was not usually identified as the main reason for admission and other problems such as falls, urinary tract infection, fractures or stroke were the primary causes of hospital admission. Furthermore, the mental health nurses took careful note of differences in behaviour or mood displayed by their patients and linked these to the specific diagnosis, whereas the general nurses did not take such careful account of these aspects of their patients' care. This is partly related to the education of the nurses but also relates to the culture of the workplace and the differing roles of the nurses. Mental health and general medical areas have different priorities. Talking to patients and studying their mood and emotions is a main function of the mental health area while this work does not have the same emphasis in a medical ward where other aspects of care take precedence. The culture of these two clinical areas is very different and alternative approaches are legitimately used by the nurses who understand and manipulate different forms of capital within each ward setting. A statement about a patient's mood would be seriously considered by staff working within mental healthcare while a similar remark in a general medical setting would be treated as trivial. The interpretation of the information is shaped by the culture of the workplace, the aims of the care setting and the distribution of capital within the setting. The struggle between the paradigmatic difference of

medicine and psychiatry is one of the power struggles which challenges the boundaries of the study field and influences the care of dementia patients.

The analysis presented above outlines something of the nurses' knowledge of diagnosis. Medical terminology is used in the data, for example, 'Alzheimer's disease', 'Lewy body dementia', 'Korsakoffs'. These terms could be used to denote some expertise and set the nurses apart from lay people. Some of these terms have now moved into popular parlance, for example, Alzheimer's disease is a term which would be recognised in society more widely. However, medical terminology used by a nurse carries a greater authority than when uttered by a lay person. Use of the terms suggests knowledge of the underlying disease processes. As outlined, however, probing during data collection suggested that much of this knowledge was superficial, especially when used by the general nurses. It could, therefore, be suggested that using medical terminology served specifically to portray an increased knowledge of dementing illnesses. Pete chooses not to use the specific terms but uses simplistic phraseology instead;

Pete: I think if, if it's dementia then if they're demented they're demented. I would then have to go em, and look up the different type of dementias to see is there anything particular... (RN)

By moving away from the more specialised language Pete appears to belittle his knowledge. This example shows the power of language in generating an impression of knowledge. Medical terminology related to specific diagnoses was used by the nurses as a means of portraying knowledge and expertise in the field of dementia care. Traditionally a 'Cinderella service', care of older people has a poor image when compared to the acuity of other clinical areas. Using specific diagnostic labels allows the nurses to imply knowledge of the underlying conditions. Manipulating language in this way allows the nurse to portray power and authority while at the same time highlighting the specific knowledge attached to this area of practice. This confers

power on both the individual nurse and the professional group of which he/she is a member, gaining status for the specialised field of dementia nursing.

5.4.2 Practical Utility

Many of the nurses felt that the specific diagnoses did not significantly influence care strategies. This was true of both general nurses and some mental health nurses although the motivations for making these remarks were somewhat different. For example, Pete, a nurse introduced previously, showed his opinion clearly in this expanded extract;

SJR: Is it important to know whether the person has Alzheimer's or vascular dementia or Lewy Body dementia? Does that make any difference to their care do you think?

Pete: To my personal care to them? No, I think if, if it's dementia then if they're demented they're demented. I would then have to go em, and look up the different type of dementias to see is there anything particular. Em, now if that was the case then I would be willing to do that. But, the way we're working just now at the moment. I wouldn't really make a fuss of going to find out what it is. I would find out how they vary individually, what do they need and I would just, to be honest, carry it forward from there (RN).

Lauren suggested that knowledge of the specific diagnosis was important in order to predict the potential course of the illness and discuss it with family members.

SJR: Do you think the different labels are helpful? Does it help you to know somebody has Alzheimer's type dementia or vascular or Lewy Body dementia, whatever?

Lauren: I think to a certain extent it does because your, your Lewy Bodies can have periods of a bit more lucidity and then the aggression can rise. Em, your arterial sclerotic, they can kind of fall and then plateau out for a while again, do it in steps. Em, whereas with your

Alzheimer's they just have a kind of gradual decline. So yes, yes it does help because you can then sometimes speak with the relatives and say well, yes they really have gone down very quickly in this past week but hopefully they'll reach a plateau and you know, they might stay at that level for a time. Yes that does help, yeah (MH).

Lauren worked in a mental health area and found the specific diagnoses helpful. However, her opinion was not shared by all her colleagues, many of whom agreed that the care was not directly related to the diagnosis and, in many cases, people with different diagnoses shared similar characteristics. Steven outlines this view and also stresses the individual nature of any dementia presentation.

SJR: Do you think it's helpful to know the very specific diagnosis, whether somebody has an Alzheimer type dementia or vascular dementia or Lewy body dementia or?

Steven: Em, well to be honest, the Lewy body, the vascular and the, the other one that you mentioned, the Alzheimer's. In terms of their presentation in this kind of setting it's not going to be greatly different from one to the other to be honest. And your approach to actually caring for them is gonna be relatively similar as well. Em, sometimes it does give an advantage if you know which kind it is eh, if the background is something like maybe Korsakoff's where there's a background of alcohol misuse leading on to a specific type of dementia. Em, that kind of dementia tends to have maybe more prominent symptoms of aggression eh, and you know anger towards staff than others. And that can obviously affect your safety in the ward. Em, but like I was saying before, regardless of what their actual root of dementia is, everybody presents differently with dementia anyway and no two patients are gonna. Even with the same diagnosed illness, they're not gonna present the same. You know one's gonna remember things that the other one won't and one's gonna behave in ways that the other one won't. There's some patients will rake through cupboards and rummage about. Other ones'll push furniture up and down. It just depends on the individual. So, I would say that in some cases it's helpful to know the diagnosis, but it doesn't really make that much difference no (MH).

The point was made on a number of occasions, that people with the same specific diagnosis present in such different ways as to render the diagnosis useless as a predictive aid or key to care planning. Individualised care was considered necessary as behaviour, mood and symptoms differed considerably between patients with the same diagnosis. Steven makes the point that in some cases this is not true, for example, individuals with Korsakoff's disease or frontal lobe dementia tend to elicit symptoms specific to those diagnoses. The use of specific diagnoses to predict the course of disease may be limited to the recognition of general behavioural trends and may not even allow this degree of prediction in many of the more common forms of dementia. Many of the nurses who participated in the study could not see the value of the specific diagnostic labels in relation to their day to day practice and did not use these labels to clarify the diagnosis even within their own minds.

In summary, the nurses from mental health and general areas demonstrated differing amounts of knowledge about specific diagnostic labels and found different values in their use. The reasons for these differences may be partly educational but there may also be a significant component which relates to the setting and to the cultures and aims of the setting. However, nurses from both educational backgrounds suggested that the value of the specific diagnosis in the care of individuals was debatable.

5.4.3 Obtaining a Diagnosis

In many cases specific diagnoses were not made or the dementia was deemed to be of mixed aetiology. In these cases the diagnostic labels were missing and this contributed to the overall lack of utility of the labels. There was also some reluctance, by nurses, to label someone with dementia. This was thought to be due to the perceived significance of the label, a point which is discussed in some detail in chapter seven. This reluctance and the reluctance of medical staff can lead to an individual failing to receive a formal diagnosis. In some cases the individual will have displayed symptoms for some time but may not have come into contact with

health services. In other cases some minor diagnostic procedures will be carried out but may be inconclusive. Marjorie, who works in a surgical ward, talks about the tests carried out if a patient displays signs of dementia in the extended post-operative period.

SJR: I think sometimes it's the anaesthetic though isn't it?

Marjorie: Aye and sometimes they come round after a few weeks and they improve. Sometimes they don't.

SJR: Do you then investigate for a diagnosis of dementia?

Marjorie: Yeah. Aye, they do look for a physical cause. They do what they call a dementia screen. Em, the doctors do that you know, various tests and that. Full blood, iron deficiency is one of them and I can't remember what the rest are but they have a few things and things Sometimes they'll do a brain scan to see if there's you know, anything there. Whether that's something that can be treated or whether it's just something that's, well (shrugs) (RN).

This ward did have a procedure in place for 'screening' those thought to have dementia. However, Marjorie did not demonstrate a thorough knowledge of the process, just an awareness of its existence. This formal process seemed to be important to the nurses despite the lack of knowledge about or regard for a specific disease label outlined in earlier pages. The authenticity of the diagnosis and the strength of the diagnostic process in granting that authenticity were highlighted by nurses. June stresses the importance of knowing that someone is formally recognised as having dementia and highlights the lack of importance attached to the more specific diagnostic label. Her contribution emphasises the need for a formal diagnostic procedure in order to lend authenticity to the diagnosis;

June: I think what we tend to do first is find out if they've actually been diagnosed with dementia or, is it a confusional state or is it that they're just a bit forgetful, their short term memory's poor or you know have they been for a scan at some time? Have they had some

vascular episode in the past? Things like that, because an awful lot of people I think are diagnose, well not diagnosed, they're termed as demented or they have senile dementia and they've actually not been seen by anybody to have actually that diagnosis made.

SJR: Have a formal diagnosis. And that makes a difference?

June: Yes, we find out that these people who were deemed demented have got actually an infection or something and they've been very confused.

SJR: Does the very specific diagnosis help if you know someone's got vascular dementia or Alzheimer's or Lewy body or whatever?

June: Well, I don't know if we'd know if it's so particular. It's just to know that they have actually been diagnosed as dementia (RN).

The importance of the diagnosis being made outweighs the importance of the detailed diagnostic information. The umbrella term carries with it a great deal of authority if it has been reached through a formal process of diagnosis. This authority is capital which is recognised within the field and puts the label, however vague, into a privileged position. The disease label serves as a badge of entitlement allowing an individual access to services and potential financial assistance. Society recognises disease labels in this way making the label a significant part of the authentication of disease. While an authentic diagnostic label carries with it status in the social world, the labels have themselves been subtly graded by society. Certain conditions carry greater kudos than others. Within this tacit grading process, conditions which elicit socially distasteful behaviours or the erosion of mental processes are usually rated poorly by society. Within the habitus of our communities, manners of speaking, dressing, ways of interacting and presenting oneself are implicitly regulated. The disruption of this delicate cultural balance can be excused by virtue of the disease label. However, the interaction of the individual with the social world is changed. As well as affording certain 'privileges' a disease label can, therefore, also lead to stigma and societal withdrawal. Further discussion of stigma is given in chapter seven. The lay members of society are not put off by the vagueness of 'dementia' as a diagnostic label. Specific diagnostic categories do not carry added weight within the social world. Only the authenticity of the diagnosis itself is important and the

capital afforded to the institution of the hospital and staff within the hospital supply that authenticity.

Within the study field, diagnostic authenticity is important. Traditionally the diagnostic role is afforded to medical rather than nursing staff. This allows nurses to 'side-step' the thorny issue of diagnosis in favour of their medical or psychiatric colleagues. Data on confusion, presented in chapter seven, show that this is an issue which nurses may be all too happy to avoid, as the responsibility of bestowing a label as significant as dementia does not sit easily on the nurses' shoulders. The data also show the nurses' preoccupation with the authenticity of the disease label. Jim talked about 'real demented people' with reference to those severely dementing patients in his care. He drew comparison between nurses in general medical settings and his colleagues in mental health care.

Jim: ... even the ones who were only mildly confused, the general nurses, you know, they really didn't know how to cope with them. *(Brief gap, one person looks uncomfortably towards me, I continue to smile a little, trying to indicate that I'm not offended by this slightly aggressively delivered point of view)* (...) I think they probably thought 'oh the person's demented'. We would have said, you know, having dealt with real demented people, we would have said that they're only mildly confused. But maybe that's because we see them, you know at the, in the end stages you know (MH).

Jim suggested that those with earlier stage dementia, who were being cared for in general settings, were less 'real' or had a less authentic diagnosis than the more severely affected individuals in his care. This remark demonstrates the nurses' preoccupation with the authenticity of the diagnosis but also shows the partial view which Jim holds of the course of dementia. This partial view became obvious throughout the data. Nurses from different clinical areas know and understand dementia from their experience in that setting. Few of the contributing nurses could give an overview of the course of dementing illness or the extreme ends of the

dementing process. Nurses working in medical wards, typically, came into contact with people in the earlier stages of dementia. They demonstrated little vision of the end stages of dementia and conceptualised dementia from this rather limited standpoint. However colleagues in mental health areas held equally limited viewpoints as they tended to focus on the end stages, working with severely dementing individuals and forming a concept of dementia based on this experience. Jim's remarks raise issues which will be dealt with in more detail in subsequent chapters. For example, chapter eight will explore the end stages of dementia in more detail, considering the views of nurses from both medical and mental health backgrounds. Some of the comparisons made between medical and mental health nurses and the clinical areas in which they work will be discussed in chapter nine along with the methodological issues arising from these discussions. However, Jim's remarks also emphasise his need for people to understand the patients that he cares for and their disease. He wants the label of dementia to be reserved for those he considers to be 'real' sufferers. This demonstrates his view of the importance and the power of the label in painting a picture for all to see, both of his patients and of the job which he does in caring for them. In reserving the label for those severely effected patients in his care, Jim emphasises the extent of the damage of dementia while also shedding light on the work which he carries out in the long stay ward in which he works. By making these remarks, Jim stressed the need for authentic diagnosis in order to ensure that the powerful label is, in his view, correctly assigned. Furthermore, he suggests that these patients require specialist care because of the severity of their presentation and this allows his own work to be regarded in this way. Often seen by society as one of the less glamorous clinical areas, the capital attached to care of older people is less than many other clinical specialities. In a society where specialist knowledge is highly regarded, the need for such knowledge increases the capital attached to a clinical area. This is a development which is starting in care of older people, with the development of gerontologist nurse specialist roles (Reed et al. 2007). An authentic and precisely used disease label, which carries with it ideas about the severity of symptoms, is an important part of the image of dementia that Jim is trying to portray. The specialist knowledge and huge depth of compassion required to work in this field are thought of positively by the

social world and result in a positive view of individuals working with this group of patients.

This analysis is not intended to undermine Jim's case but rather to make explicit some of the power dynamics within the field and ways in which society works to develop concepts. Using Bourdieu's writing as a guide for this work requires remarks which are readily understood during conversation to be unpicked during analysis. Actors within any field will work to maximise capital. This drive may challenge the boundaries of the field, developing the field in previously unexplored ways, may promote the individual at the expense of the field, or may promote the field and the individual simultaneously. This analysis must tease out the motivations of actors in order to develop a full picture of the field. The analysis of Jim's contribution suggests that Jim may be promoting himself as well as his clinical area. This analysis is not intended to be a criticism of Jim himself who is merely trying to show himself strongly within the field. There is no doubt that my own position as a general nurse conducting a focus group within a mental health setting contributed to the dynamics of the interaction from which these data were generated. This emphasised Jim's defence of his specialist role and set up an artificial opposition between clinical backgrounds in which Jim defended his own position fiercely. Reflecting on the data generated in mental health settings, I would not disagree with many points raised by Jim. The long term mental health settings differ markedly in both aim and culture from the acute general medical settings, as outlined earlier in this thesis. The skills required to work in long term care areas such as these are, in my personal view, extremely specialist and require depths of personal commitment and compassion which are different to those found in many other areas of nursing. Whether these differences can be accounted for by different types of nursing education and contrasting medical or psychiatric work experience is, for me personally, a more challenging question which I will return to during the discussion chapter of this thesis. Jim's emphasis on the authenticity of the disease label and his desire to ensure that it is connected to 'the correct' individuals is partly to ensure the integrity of his specialist client group but also reflected views of other nurses.

Simon touched on the imprecise use of the term dementia and seemed to suggest that this was unsatisfactory.

Simon: Most people tend to like the general term dementia meaning anybody losing it over the age of 65! Doesn't matter what's happening to them, it's dementia! (MH)

While Jim and Simon both allude to specific views about the label of dementia, some nurses seemed reluctant to use the term dementia at all. When asked to point out 'dementia patients' during the observation phase of the study, some staff reported that they were sure that the patient concerned had dementia but, in the absence of a formal diagnosis, they were not 'real' dementia patients. This demonstrates the power of the doctor or psychiatrist within the field to bestow disease labels and the strength of the structures within the field of hospital care to determine diagnostic procedure. Furthermore, it indicates the significance of the label itself and hints at a stigma surrounding the label which will be discussed more fully in chapter seven.

In conclusion, ideas about disease, treatment and cure underpin much of Western medicine. This medical model dominates nurse education and the culture of the field of study. The concept of disease, therefore, influences the way in which nurses think about dementia. While many of the nurses conceptualise dementia in terms of disease, they do not always make links to specific diagnoses of dementing illness. The data suggest that this is partly due to a lack of knowledge about the diseases but is also related to the perceived lack of utility of these labels in practice. The conceptualisation of dementia as disease is, therefore, based on very general ideas about disease rather than the specifics of particular diagnoses. There seems to be a need to complete a formal diagnostic process in order to give the general label of dementia the recognised authority of the field.

Continuing to follow the shape of the medical model, so influential in the field of inpatient dementia care, this chapter will now consider data about the progression and treatment of dementia.

5.5 Dementia as Disease - Progression and Treatment

Talk of progression, degeneration and decline are acceptable within the context of disease. Progression is part of the nurses' understanding of some disease processes. It was raised on a number of occasions, sometimes as part of a definition of dementia and other times as part of general discussion about dementia, for example;

Penny: I see it is a degenerative system resulting in kind of loss of memory, and also has to do with the person will not be able to do the normal activities of daily living, resulting in loss of self esteem, conflict with relatives develops (RN).

Ava: Well, as I understand it, it is degeneration of your brain so obviously other things are going to go. I mean, I suppose it's like anything else, the rate of progression (interrupted) (RN)

Penny and Ava talk in very clinical terms when describing the progression of dementia. The terminology and language used by the nurses when discussing dementia as a disease is reflective of their nurse education, work environment and culture. This clinical vocabulary serves to medicalise the process of dementia. It objectifies the symptoms and helps nurses to distance themselves from the personal deficits and declines evident in their patients. By using clinical terminology and portraying dementia as a disease, the nurses make the disease process less personal, a process which may serve to alleviate some of the distress of the condition or distance the nurse from personal fear of dementia. This idea will be discussed in greater detail in chapter seven.

By using disease related terminology the nurses are using language with which they feel comfortable. The language of disease could be seen as a barrier between the nurse, the distressing features of dementia and its personal face in the patients for whom they care. Furthermore, the language is a bond between the nurses who, as an occupational group, use and understand this terminology while patients and family members do not share in the ease of this dialogue.

Functional decline was mentioned by many of the nurses including Penny in the extract quoted above. The contributing nurses chose to focus on function and particularly on patients' abilities to complete activities of daily living independently. This was used as a measure of an individual's dementia, indicating arbitrarily the stage of development of the dementia. This is far from uncommon. Alzheimer's Scotland use similar 'measures' to explain the stages of dementia on their website;

“Generally, the progress of the disease is broken into three stages; mild, moderate and severe.

- In mild dementia, a person might have difficulty making decisions, coping with complexities in their work or hobbies, and may have problems remembering to pay bills or attend appointments.
- At a moderate stage, the person with dementia may have increasing difficulty recognising family, friends or familiar places, may need more help with everyday activities such as reading or dressing, and their behaviour may change.
- In the later stages of dementia, the disease affects more functions of the brain, and problems of memory and everyday activity become more severe. Communication can become very challenging and the illness is likely to increasingly affect the person's physical abilities.”

(Alzheimer's Scotland: Action on Dementia online accessed 21/09/08)

This focus on function can be very helpful to lay people trying to understand and quantify the problems that an individual is having. Functional ability is hugely significant in determining the work of the nurse in both medical and mental health areas. However, the focus on function seems to prevent any kind of overview of dementia progression more generally. While the disease label opens the way for the discussion of decline and the use of such words as ‘degeneration’ and ‘progression’, the focus on function dominates the nurses’ views of this progression. This focus has implications for care which will be considered later in this chapter.

5.5.1 Planning for Progression

In recent years it has been accepted that making an early diagnosis of dementia reflects good practice (Page et al. 2008). This allows the individual and his/her family to make plans for the future and discuss some of the choices which may need to be made. Fundamental to this opportunity, however, is the ability of the nurse to facilitate this process through an understanding of dementia which includes insight into some of the challenges which may lie ahead of a newly diagnosed individual. During one focus group the nurses suggested that early diagnosis of dementia and the use of a disease label allowed the individual and their family to prepare for and understand the development of symptoms and progression of the disease.

SJR: So how do you think it helps people to have a diagnosis of dementia so much earlier then?

Lynsey: I think early onset dementia tends to be more progressive, quicker. It’s quite sad actually.

Joanne: I think it helps the families to know what’s going to happen.

Felicity: I think as well sometimes for the patient themselves, depending on the degree, there’s less a sort of feeling of usefulness that you would get if there wasn’t a diagnosis of dementia or that. They keep thinking I’m getting old, I’m getting dodderly, I’m getting this, I’m getting that. Where if they can actually be told ‘it’s not you. You have a medical condition.’ It might be easier for them to come to

terms with and easier for their family to come to terms with seeing their parents sort of degenerate before their eyes which is one of the saddest things about dementia is the effect it has on their family. (MH).

Felicity stresses the importance of the disease label in helping both individual and family start to adjust to the effects of dementia. As a nurse I can identify with this process of diagnosis, adjustment and planning for the future. The hospital nurse has a role to play in helping an individual to begin this process while colleagues who have continued contact with a patient over time may be of assistance to that individual throughout the long and very personal process of adjustment. Each individual will benefit from different types of support or amounts of information and will wish to have different amounts of forewarning about potential future challenges. In much the same way as a nurse would support a newly diagnosed diabetic to monitor blood sugar independently, give insulin, be aware of short and long term complications and live a full, healthy life, a nurse should be able to support a newly diagnosed dementia patient with information, advice and strategies to deal with difficulties as they arise (National Institute for Health and Clinical Excellence (NICE) 2006). Against this backdrop it was surprising that the focus groups generated very limited data about the progression of dementia or planning ahead. Planning or preparing for the progression of disease is a topic which was mentioned very briefly by nurses and was generally dismissed when specific questions were posed. The lack of data in this area is interesting and may be indicative of a variety of things. Firstly, nurses may not wish to focus on some of the difficulties which could lie ahead for an individual with dementia. This will be addressed in greater detail in chapter seven and later in this chapter when treatment options are discussed. Secondly, hospital nurses may be unaware of the full scope of dementia, seeing either early or end stages in isolation depending in which area they work. Structural aspects of the field exacerbate this problem by separating groups of patients by virtue of the symptoms which they display and the nursing expertise required. This point was made earlier in this chapter and will be highlighted again in the discussion in chapter nine. A third reason for the lack of discussion of the progression of dementia may simply be lack of

knowledge. Data presented earlier in this chapter suggest that many contributing nurses may have imprecise knowledge of specific dementing conditions. The extent of potential decline may be unrecognised by many nurses who do not fully understand the neuropathology associated with dementias of various types. Equally, they may be unaware of some of the positive accounts of life with dementia which have become prevalent over recent years.

Furthermore, Simon highlights the difficulty of predicting what is ahead for someone with dementia;

Simon: I suppose that's the other problem with dementia is that because it can, it can change the rate it progresses quite a lot, you get a lot of misplaced people because they'll end up somewhere and then the dementia'll accelerate and they'll become a lot more disturbed and so you get, probably with dementia more than a lot of other conditions, it's really hard to construct units and put people together well because no two people are alike. And so you end up with mixed units of severe right down to mild dementia. (MH)

The unpredictability of progression in dementia is significant not only for the placing of people with dementia, as outlined by Simon, but also for planning more generally. This point was raised repeatedly by nurses who emphasised the need for individualised care for each dementia patient. The unpredictable course of disease was also raised earlier in this chapter with reference to the utility of specific diagnostic labels. While the course of some types of dementia may be easier to predict than others, the typically fluctuating course challenges the nurse trying to help a patient to plan for the future. The repeated call for individualised care is one response to this challenge which will be discussed in chapter six. However, the problems associated with predicting the course of dementing illness emerge from the data as a significant cause of the limited view of progression or planning by nurses.

Finally, Lynsey's remark in the extract from the mental health focus group on a previous page makes clear reference to those with early onset dementia. This raises a question about whether progression of dementia and planning for the future may have added significance for those affected younger. The data certainly do not demonstrate that nurses caring for older people give high priority to this planning and preparing process. Indeed age itself may pose a barrier for nurses who find that increasing age makes the progression of dementia less clear. Older people often suffer from additional health problems which have the potential to shorten their lives. As a result of this and of their age, the progression of dementia to end stage may be seen less often in older people than in those who are younger, thus giving nurses an unclear view of the progression and end point of dementia. Marjorie highlights the fact that many patients die from other conditions and do not reach the end stage of dementia.

Marjorie: Aye, it changes your life forever, definitely. I mean obviously people would die from it if it's just general atrophy then obviously there's part of the brain atrophy as well. But I mean, most of the time they don't actually die from dementia do they? They die from other things (RN).

Marjorie's comments show that the experience of dementia from the workplace shapes the nurses' understandings and overall image of dementia. This experience may contribute to the lack of data about progression and the lack of importance attached to it in favour of the nurses' drive to promote function. However, Marjorie's initial statement, underlined above, speaks volumes about her view of dementia and highlights the need for nurses to take on the role of helping people to prepare for the future, making positive choices about their changing lives.

5.5.2 Limited Treatment Options

As outlined previously, the medical model promotes an understanding of illness in terms of diagnosis, treatment and cure. Conceptualising dementia in terms of disease raises questions in each of these areas. While issues surrounding diagnosis have been discussed and some attention has been given to the progression of the disease, issues of treatment have not yet been addressed. Treatment options for those who have dementia have varying success. Pharmacological interventions seek to prevent the progression of cognitive decline in mild and moderate dementia of Alzheimer's type. Drug treatments have hit the headlines in recent years as their availability has been curtailed because of doubts about efficacy (Dyer 2007; National Institute for Health and Clinical Excellence (NICE) 2007; Voelker 2008). Some people derive huge benefit from the drugs and notice marked improvement in functional abilities. However, these therapies can have significant side effects and some individuals fail to respond to the medication (Dale et al. 2003; Hogan & Patterson 2002; Onor et al. 2006; Rozzini et al. 2005). Other therapies and services can improve function and quality of life and are vitally important in the lives of many individuals, for example, herbal remedies, social contact and stimulation, day care, reminiscence, computer programmes. However, there is no cure for the majority of dementias found in older people and there is a certain inevitability about eventual decline, albeit over widely varying timescales.

This lack of treatment options seems to be significant for the conceptualisation of dementia as a disease. Many of the nurses made remarks about dementia being 'untreatable', a view also reported in the 2006 guideline from the National Institute for Health and Clinical Excellence (NICE). The 'untreatable' label seems to challenge the nurses' ideas about disease, learned within a paradigm which focuses on treatment and potential cure. For example, Marjorie outlined the limited treatment options in dementia and suggested that this made her consider dementia to be part of getting old rather than a disease process.

Marjorie: I think it's tragic and I think that nowadays we're able to treat medical conditions and people are living longer but the brain cells are dying off. It's we haven't been able to treat that I don't think, very successfully. But it seems to me to be a huge problem in the elderly and it just. I don't know if it's getting more and more. I haven't worked in care of the elderly an awful long time. It seems to me that it seems to be getting more and more, but maybe not. Maybe it's because I'm in this area now and I wasn't before.

SJR: I think if people live longer though it definitely becomes more of a problem.

Marjorie: Mhm, yeah. I think we were treating all these things that people would have died for maybe 20/30 years ago. So here wasn't a huge problem, a tragedy, then but there is a huge problem now because we cannae treat the brain atrophy can we, no very successfully.

SJR: So, so it's a tragedy to start with?

Marjorie: Aye yeah. I think that's

SJR: Would you say you think of that as a disease or part of getting old or?

Marjorie: I think I see it as part of getting old maybe, we can't do anything about it, so yeh (RN).

Marjorie's view shows that treatment plays a vital role in the nurse's conceptualisation of disease generally and, therefore, influences views of dementia more specifically. The privileged position of disease within the field is clear and the power of the concept of disease is significant in shaping this nurse's thinking. The label of disease leads to assumptions or expectations that nurses and doctors have the power to cure or at least treat. Cancers which can not be cured are often treated in order to alleviate symptoms or improve longevity and quality of life. In contrast, dementia is understood to be both incurable and untreatable. As such, dementia challenges the very foundations on which the field of inpatient dementia care is built. This view of dementia as untreatable erodes the power of both nursing and medical/psychiatric staff. The structures of the field of inpatient care require the nurse to be in a position to offer something to patients or family members as part of

the exchange of capital. In this example, the 'currency' of the interaction is treatment, with the nurse offering his/her skills in treating the patient in exchange for the professional respect and recognition from the patient and family members. Without this 'currency' the power dynamics change and structural aspects of the field are challenged. As a way of avoiding this powerlessness, Marjorie chose to conceptualise dementia as part of normal ageing rather than as a disease. Understanding dementia in this way requires nothing of the nurse and, therefore, alleviates the powerlessness.

As a nurse and a researcher reflecting on this analysis, I feel uncomfortable with the simplicity of this explanation. While this analysis makes sense of the data and readily explains the nurses' views and their interactions with patients, I feel a sense of unease that the stature of the nurse should live or die by the treatment options available. During the observation phase of this study, nurses were observed engaging in conversation with the most repetitive of individuals, patiently explaining answers to repeated questions with unerring good humour and genuine interest. In another ward a nurse walked the corridor, up and down, holding the arm of a woman who wanted to collect her children from school. Another nurse brushed the hair of an elderly woman who was often agitated. Stroke after stroke the nurse continued to brush until the woman drifted to sleep, a memory of childhood and the care of her mother offering the reassurance that she needed in order to sleep. These nurses could offer their patients no formal treatment but they were not powerless to offer something to the individuals in their care. Many of the contributing nurses did feel that the limited treatment options undermined their position within the field. Some of these nurses were unaware of the plethora of therapies and strategies which could have been beneficial while others simply felt powerless in the face of poor drug treatments and lack of curative potential.

On reflection, it seems that the structures of the field themselves contributed to this powerlessness by overemphasising the need for formal treatment in the form of drugs

or therapies, or nursing interventions such as feeding, toileting and bathing. By failing to attach value to more nebulous concepts such as comfort, security or compassion, the actors within the field contribute to their own powerlessness, undermining their own positions. As an observer, it was clear that many of the nurses who offered the least formal intervention made the most significant contribution to their patients, instilling quiet security or making the individual feel valued in a way which the structures of the field fail to recognise.

In summary, discussion of the progression of dementia is made acceptable by the conceptualisation of dementia as a disease. This context legitimates the discussion of potentially distasteful symptoms, as progression is understood to be part of some disease processes. Contributing nurses focus their comments about dementia on functional ability, a focus which may limit their overview of the progression of the disease. While early diagnosis has become an important feature of good quality dementia care, nurses do not appear to plan ahead for the progression of dementia post diagnosis. This reluctance may be due to lack of knowledge, limited experience of the full spectrum of dementing illness, or the unpredictability of the course of dementia. Furthermore, societal attitudes to older people and the complexity of multiple pathologies may make planning for the future more of a challenge and less of a priority in this client group. Treatment is an important feature of the medical model and is integrally linked with the nurse's perception of his/her position within the field. While some significant treatments and therapies are available and many strategies can significantly improve the lives of individuals with dementia, the nurses conceptualise dementia as being untreatable. This challenges the nurses' view of their own role and their understanding of dementia as a disease.

The contrast between dementing illness and the ageing process provides a backdrop to much of the data generated in this study. The following section highlights some of these issues and considers ways in which nurses use the concept of disease to make sense of this dichotomy.

5.6 Disease and ‘Normal’ Ageing

Some of the nurses used a disease label to distinguish between dementia and what they saw as ‘normal’ ageing. In some cases this was as a direct result of dementia training sessions which had been run for nursing staff within the hospital. The disease label was seen to be helpful in drawing comparison and making a contrast with ageing per se;

Ava: I see it as a distinct sort of disease process rather than just being a general term for elderly confusion or elderly forgetfulness (...)

SJR: I’m quite interested that from your training you’ve learned to see it as a disease. Do you think that’s quite helpful.

Ava: Yes, otherwise it’s just seen as something, like getting a bit short sight, poor sight or deafness like elderly people do (RN).

For Ava the contrast between the process of ageing and dementia is an important part of adding gravitas to the diagnosis. The significance of the diagnosis is lessened by its link with the ageing process, while a disease label seems to boost the status of the experience of dementia. Ava’s remarks demonstrate how her conceptualisation of dementia as a disease is influenced by the dominance of medicine as a discipline within society. The perceived lesser importance of dementia when directly linked to ageing makes comment about the negativity surrounding ageing and the unequal distribution of capital within society. The relative power of medicine, both within the hospital and in the wider society, means that the perceived significance of dementia, when viewed as a disease, is elevated. This links with the framework of capital distribution within healthcare, outlined in the power distribution diagram in Appendix two. Ava, as a nurse, understands the language of disease and the position held by the disease label within society. However, she is also aware that family members might be able to use this information to their benefit. She notes;

Ava: I think that a lot of relatives don't understand, emm, cause dementia's confused with generally just getting old and I actually, sometimes, I haven't personally done it, but I've overheard other nurses explain to their patients that what is happening to their relative is the disease process and that they won't get any better. I think that is something, people think they might get a bit better and you have to confront the fact that they're actually going to get worse. I think in the community dementia's looked on as not, maybe not as serious as it really is. Maybe even as slightly funny ... or, like in Eastenders just now they've got the Granny with dementia and (giggles) (RN)

The disease label can stress the seriousness of the diagnosis and contrast it with normal ageing by outlining the potential progression.

The link between dementia and getting older was mentioned a number of times during the data collection. Helen pointed out that some elderly people themselves believe their symptoms to be a normal part of the ageing process.

SJR: Would you ever consider speaking to a patient with dementia about their dementia?

Helen: Yes, I've tried sometimes. Because sometimes they do know that they're confused, but. But I think that they just think that it is part of getting old and forgetful (RN).

This extract describes Helen's experience of broaching the subject of disease with her patients. The response from patients may reflect the fear associated with a disease label and the finality of this particular label. Older people might prefer to consider their symptoms to be part of the normal ageing process than to think of themselves with a disease such as dementia. The extract also suggests that older people may have expectations of old age including cognitive decline. These expectations could be developed from the media, popular culture or from personal experiences. Some of the nurses who contributed to the study may also have had

these expectations. Few expressed them explicitly during the interviews but many informal comments during interview and observation periods suggested that nurses caring for older people may expect a level of cognitive decline. For example during one interview Angela made the following remark.

Angela: (...) Well I mean although it's rehab and we go from the range of 20 year olds to, we've got a 96 year old in, it's, aye, and she hasnae got dementia either I'll tell you. She's right on the ball. But em, ... (RN)

Angela felt that it was worthy of remark that her 96 year old patient does not have dementia. She did not explicitly report her expectations but by making this comment she suggested that this situation was outwith the ordinary. Victoria remarked that, at least part of her understanding of dementia, related the features of disease to the normal ageing process.

SJR: Would you say you think about dementia as a disease or as part of just getting old or as something that you might die from or that changes your life forever or? How would you say you see it?

Victoria: Partly as a disease and partly as getting, it, sometimes it's getting older. Em, yeah (RN).

Marjorie made the following remark about her expectations of post-operative patients in her care;

Marjorie: We look at the patient. It doesnae matter what they have in the background. They maybe not have dementia in the background but then we might decide oh I think maybe they've got a wee bit of dementia here. I wouldn't say it made any difference, cause you kind of expect it you know (RN).

Nurses and patients alike may expect some degree of cognitive decline in old age and the disease label formalises the process in a way which might be unacceptable or frightening to some older people. For the nurses, however, the label of disease is helpful in order to differentiate between the natural process of ageing and the effects of dementia, adding significance to the dementia label. Furthermore, the disease label has the added advantage of distancing families and nurses from the fear of developing dementia. As outlined by Felicity earlier in this chapter, the label of disease served to distance the symptoms from the ageing process and made it easier for an individual and family members to accept increasingly apparent symptoms and deficits. She explained;

Felicity: I think as well sometimes for the patient themselves, depending on the degree, there's less a sort of feeling of usefulness that you would get if there wasn't a diagnosis of dementia or that. They keep thinking I'm getting old, I'm getting dodderly, I'm getting this, I'm getting that. Where if they can actually be told 'it's not you. You have a medical condition.' It might be easier for them to come to terms with and easier for their family to come to terms with seeing their parents sort of degenerate before their eyes which is one of the saddest things about dementia is the effect it has on their family. (MH).

The comparison between the disease label of dementia and 'normal' ageing seemed to be important for two reasons. Firstly, the nurses wanted to highlight both the seriousness and authenticity of the symptoms associated with dementia by specific use of a disease label and, secondly, they hoped to distance themselves from the dementing process using the disease label as a symbolic barrier between themselves and the process which damages only some individuals. Ava highlights this in the following extract;

Ava: I see it as a distinct sort of disease process rather than just being a general term for elderly confusion or elderly forgetfulness. Having had the dementia training from(forgotten name)

SJR: Yes of course, from Carol, Carol Archibald?

Ava: Carol Archibald, yes, I thought that was helpful because, it takes a lot of the fear out of dementia. Like not everyone gets it although you expect people in their nineties to be a bit forgetful or... Also the loss of personality involved as well, as was explained rather than just becoming ... dithery! (RN).

By considering dementia as a disease process, Ava can distance herself from dementia. The fear of developing dementia is lessened by considering it to be disease and, therefore, not an inevitable part of growing older. This distancing carries the authority of the field and nurses are encouraged by education and training to objectify dementia in this way. Carol, a Charge Nurse, made the following remarks about her focus on dementia as disease while discussing the education and training available to her ward team. She commented;

Carol: We're probably sort of trying to get them to think of it as being a disease.

SJR: Yes

Carol: Because it is. And it's alright to have cancer. You know, it's a stigma of having dementia. It's alright to have cancer because that's a sort of attractive, well it's not attractive ...

SJR: No, no, but ...

Carol: But it can be seen as ...

SJR: Perhaps it has more glamour or a higher profile ...

Carol: Yeh, so we're trying to get them to see it as a disease like any other. Like heart disease or lung disease or whatever and that way they're not, you know, stigmatising the people even more just because they're having dementia. They've got the right to that. And, we have got the videos. We're trying to set up a room so that they can see them all. But we, we try to get them to see it as a disease like any other and if you treat one disease then why should this be any different? (RN)

The nurses were not asked explicitly about their personal fears about developing dementia and it is, therefore, difficult to comment on this aspect of their ideas. However, the need to be in control of life and make decisions autonomously is a universal drive and a societal expectation. The society in which we live requires individuals to be cognitively adept. This is, increasingly, true of older people who now need to use pin numbers to access their pensions and face choices in the provision of everything, from their utility suppliers to their care services. Against this backdrop, it is not unreasonable to suppose that the nurses, along with a large proportion of the population, fear the loss of cognitive ability which comes with dementia. Conceptualising dementia as a disease and setting it apart from the ageing process serves to create a protective barrier for the nurses. Furthermore, this distance was beneficial when caring for the patients, as it allowed nurses to attribute potentially disruptive or aggravating symptoms directly to the disease rather than to the patient personally. This will be discussed further later in the chapter.

5.7 Conceptualising Dementia as Disease in Practice

The curiosities from which this study emerged developed in nursing practice. Personal and nursing experience of dementia led to my own views of the diagnosis and, much like Marjorie who was introduced earlier in the chapter, my own overriding view was that dementia changes your life. This view has shaped my nursing practice, providing a backdrop to the care which I have given to many older people with dementia over my years in practice. My aim in exploring how other nurses conceptualise dementia has always been to ascertain how their understandings relate to their care practices. Does a nurse who understands dementia to be nothing more significant than a forgotten shopping list, treat an individual in the same way as the nurse who conceptualises it as a terminal illness? Having presented data in support of a conceptualisation of dementia as a disease process, making remarks about practice throughout, this section will bring together data about care and care planning, discussing issues as they emerged from the data.

The concept of disease, as outlined previously, pervades all aspects of the study field. Most of the participating nurses talked about disease at some point in their data. Analysis showed that the nurses felt comfortable conceptualising dementia in these terms as the language was familiar and fitted well with the dominant paradigms of the workplace and, consequently, with the structures and habitus of the field. The fact that some nurses choose to conceptualise dementia in this way should not come as a surprise, as this approach is used in understanding many other clinical syndromes and is reflected in approaches to education and in ward organisation. However, this thesis could end at this point if the conceptualisation of dementia as disease was as universal and simplistic as this account suggests. Throughout the preceding presentation of data, it is clear that certain aspects of dementing illness exist which challenge this conceptualisation and motivations for nurses' understandings which require further exploration and analysis. Furthermore, some of the contributing nurses chose not to see dementia as a disease but rather to take approaches presented in the following chapters.

The analysis presented so far shows that nurses talk in terms of disease and use the language associated with disease. However, it also shows that knowledge is, at times, superficial and can not always be related to care practices. For example, the data demonstrate knowledge of diagnosis but some nurses do not understand that specific diagnostic labels exist alongside the umbrella term of dementia. Some contributors used terms such as dementia and Alzheimer's interchangeably while others knew of the existence of multiple specific diagnoses but could not list more than one. While data collection for this study was not intended to be a knowledge test, the nurses did demonstrate some significant gaps in their knowledge about diagnostic labels. Further to this, many of the nurses who were aware of specific diagnoses did not use them to guide their practice. Reasons for this were outlined earlier in this chapter, for example, lack of knowledge, limited practical utility of the labels and the unpredictable course of dementia.

The nurses seem to talk about disease as a means of conceptualising dementia without considering the specifics of what the diseases entail or how the symptoms of these diseases might fit together. They focus explicitly on the umbrella term 'dementia' rather than on specific diagnostic labels and use the language of disease to create a dementia 'mirage'. Unlike other disease processes which have diagnostic criteria, pathology and treatments, dementia is understood much more generically by the contributing nurses. Much like using a diagnosis of 'endocrine disorder' in place of specific labels such as type I or type II diabetes, the nurses focus on the word 'dementia' using the language of disease which they know so well to formulate an understanding, where specific diagnostic and prognostic details fall short. This is not to say that the nurses were intentionally misleading in their portrayal of dementia as a disease. The data show that they shared their ideas openly and spontaneously, focussing on disease for large periods of interview and focus group time. They conceptualise dementia as a disease in a natural and honest manner which reflects the dominant paradigms of the field. Only through the process of analysis, have the limitations of the nurses' conceptualisation been realised.

With dementia conceptualised in this way, ideas about disease, so dominant in the field, are indeed used to shape practice. Practice was observed in all but two of the study wards. This allowed insights into the organisation and practices of a number of wards. The conceptualisation of dementia as disease shaped practice in four main areas; practicalities of the ward, medical approach to care, focus on function and finally, the nurse/patient relationship. Each of these will be discussed in turn in the coming pages.

5.7.1 Practicalities of the Ward

Firstly, understanding dementia in terms of disease had important implications for the practical and organisational aspects of the wards. While each of the wards had core staff members, there was often opportunity to increase staffing levels in

response to the dependency levels of patients in the ward. The process of charting this dependency relied heavily on disease orientated information. Diagnosis, medication, cause of admission and treatment plans were all required in order to make the case for extra staffing. This was most often observed in general medical settings where patient turnover could change the dependency profile of a ward dramatically over a short period of time. Conceptualising dementia in terms of disease allowed patients with dementia to be considered alongside those who were acutely unwell. This allowed the disease orientated system of the hospital to be used to the ward's benefit, manipulating staffing to better meet the needs of the current client group.

Bed spaces in the medical wards were also arranged around the concept of disease. Acuity and specific symptoms were taken into account while deciding where to place an individual on the ward. Diagnosis and a verbal handover from another nurse were also used in order to determine which bed a patient would be assigned.

SJR: Do you think when, somebody comes in then with that diagnosis written on their sheet, their admission sheet or whatever, what kind of things go through you mind? What kind of things do you think about?

Alison: Probably where you want to put them that they're going to get an eye on. We tend to put them opposite the nurse's station so they'll sit in front of us. Eh, so we'll keep a better eye on them. The same for the night shift. They sit there, keep an eye on them. So when we know somebody's coming in we do try to plan that. Eh, or it might just be that we need a side room or. So we do try to place them appropriately eh, but other than that I ... say we get staff in or anything like that, no other. Depending on how bad their confusion is, normally we get patients for 4 teams. Split them equally (RN).

Dementia was fitted into this structure in the same way as any other diagnosis might have been. During observation, no specific diagnostic labels were handed over,

simply the term dementia. However, this did not hamper the nurses in their organisation. The over-riding concern of nurses making the decision about which bed to put an individual into was about risk. The concept of risk pervaded all aspects of care, particularly in the more acute areas within medical or mental health wards. This is reflective of the social world in which we live and the expectations society makes of nursing and medical/psychiatric staff. Risk of falling was a primary concern while other risks such as wandering away from the ward, aggression, disorientation and crying out were other considerations. Some of these aspects of care will be discussed more fully in chapter six. However, for the purposes of organisational decision making and risk assessment, both formal and informal, conceptualising dementia as a disease proved to be both useful and intuitive.

5.7.2 Medicalising Care

The second main area where the conceptualisation of dementia as disease can be understood in practice, is in the focus on disease and the medicalisation of care which was evident throughout the study field. General medical areas could be expected to have this focus but the emphasis on medical approaches within mental health was surprising. The mental health wards observed had very heavily dependent patients who required large amounts of physical care. This perhaps makes these settings less typical of mental health care settings in general and more typical of long term dementia care settings. The nurses in these wards were much more insistent in their interviews than those from medical wards, that dementia should be understood as a disease. This was carried into their practice where they highlighted the pathology consistently while addressing the constant needs of the patients. For example, they explained a patient's incontinence in terms of damage to the brain and gradual erosion of control. This awareness of pathology was demonstrated by the nurses frequently as they went about their work, helping individuals to the toilet or dealing with incontinence. In contrast, nurses in other wards did not demonstrate an awareness of pathology in this way. During observation of a hectic shift, one nurse expressed her dismay that so many of those who have dementia are also incontinent as her team of staff was overstretched. When asked if she understood dementia and

incontinence to be linked she remarked that it was just an annoying coincidence that so many individuals had both. The awareness of the pathological effects of dementing illness contributes to an understanding of dementia as a disease process. Using this knowledge to inform care may medicalise the approach to the patient but does allow for considered nursing care of the individual. By conceptualising dementia as a disease and making links between brain pathology and an individual's presentation, the nurse is able to foresee potential problems and give high quality care. This does not require the nurse to predict the future or consider prognosis as discussed earlier in this chapter but, rather, to make a detailed and dynamic plan for the care of an individual in the immediate or short term care period.

The disease focus which pervades many aspects of practice can be seen specifically in planning for medication. Lauren explains how some medication needs to be adjusted, depending on the specific diagnosis of the patient;

Lauren: Plus medication. You know, you alter medication to their physical capabilities tolerating it. Em, be it that they're falling or not eating so well because they're over sedated and you have to continually be reassessing what you're giving them to have them at their optimum level.

SJR: It's just trying to balance the medication ...

Lauren: Yes, definitely. I mean if you use too much then obviously that's totally inappropriate. But if you don't use enough they can become distressed because they're agitation rises and they don't know. I mean they can be running up and down the ward exhausting themselves so you have to find them the happy medium. And as you know, the elderly take medication and absorb it differently ... Yeah they metabolise it differently and especially so with your, your dementia patients. And that's another thing. With your Lewy Bodies, you know give them some of the anti-psychotics or similar medication, they're far less tolerant to certain medications than the Alzheimer's. they have a different reaction to it (MH).

In one ward it was possible to observe the way in which organising workload with a disease focus actually contributed to fewer medical interventions. Dehydration may exacerbate confusion and is often a challenge when older people have infections. Many of those admitted to hospital have underlying infections which present as acute on chronic confusion, a topic discussed more fully in chapter seven. One Charge Nurse reported that preventing dehydration is a primary goal of her team. She organises ward care with this in mind and has succeeded in cutting considerably the use of intravenous therapy in her ward. This, in turn, has the benefit of reducing infections which develop secondary to giving intravenous fluids.

Susan: ... I think for a lot of our patients, it is, it's the basic things they need like getting them rehydrated and that. It's a big problem. We are actually the one ward that uses very very little I.V.s and sub cuts.

SJR: Yeh?

Susan: And it's because we make a point that it be, and I know people will say it's like task orientation or just nursing the disease but, if we've got someone that's come in with an infection we make sure that somebody that's looking after, there'll be one person ... that's going in to look. Because if we say tell the team it's the usual, well I thought they were doing it. So we just are nominating but me and Carol have been completely blunt with it. We'll say right Charles, you're going to make sure that Philip's getting a drink every hour because if we see a gap there we'll come and ask why he's not had it and it could be a valid reason but we'll just want to know why.

SJR: Yes, just checking.

Susan: Aye, because at least we want to have half a cup of fluid into him every hour and that to us has made a big difference.

SJR: So really the very simplest things.

Susan: Yes, complicated disease for the brain and that but it's the simple things you know? Even the medical staff have picked that up because, as I say, compared to all the other wards we use [IV] fluids so little. We tend just to use when we've got someone actually really quite, well ill (RN).

Susan clearly understands dementia to be a disease and uses a disease focussed approach to care. However, using this approach actually reduces the need for more significant intervention. This extract shows her slight discomfort in explaining that this aspect of ward organisation is so focussed on one feature of disease. The culture of the setting suggests that this is an outdated approach which has been overtaken by the drive towards person centred care. Capital is attached to the individualised approach to care which can promote a more personal service shaped to the individual needs of patients. The allocation of tasks or nursing patients using the disease, rather than the person as a framework, are organisational approaches which are no longer popular.

Hospitals are organised around the concept of disease and, as such, the label of disease carries with it power. This was outlined earlier in the chapter but is relevant again at this point when discussing how the conceptualisation of dementia as a disease relates to practice. The following data show remarks from a Charge Nurses who suggests that the focus on disease is the right of an individual being cared for within the structures of a hospital. This view was also held by Carol in data presented in section 5.6.

SJR: I'm hoping to find out from yourself and Carol what you want the nurses to be thinking or how you think as a ward it should be (interrupted)

Susan: Yeh, well, I think from my own personal point of view and that, I mean I do see it as an illness like any other illness that effects people's functional ability and daily activities. And like every other patient who comes in here whether it be through chest infection or whatever, they have to be assessed in exactly the same way. We're here to meet their needs and it's whatever needs that they have a deficit in that we are looking to ... try and get in whatever member of the team to try and improve that or support in any way. (RN).

Susan and Carol, as ward leaders, recognize the significance of disease within the field. The capital attached to the concept of disease means that the label enshrines the rights of patients. A disease label entitles the patient to assessment and subsequent care as outlined by Susan above.

The conceptualisation of dementia as disease is carried into practice through the approaches to care and the structures of the ward. Understanding links between pathology and features of disease helps the nurses to use this conceptualisation in their practice. Indeed, those who do not have that understanding can be challenged by features of the disease. This will be highlighted, once again, when discussing the nurse/patient relationship. The structures and power dynamics of the study field are also influential in operationalizing this view of dementia. Dominant culture in the form of ideas about care and risk, along with the rights of patients, challenge and shape the boundaries of the field and the reality of patient care.

5.7.3 Focus on Function

The nurses' focus on their patients' functional abilities was something which was taken for granted until data analysis was well under way. As a nurse, I understood the language of function used by nurses to explain issues of patient dependency, workload and ward organisation. However, returning to the data after a period of time away, allowed the full emphasis of this focus to become apparent. The nurses understood dementia as a disease with functional difficulties as symptoms. This can be seen in Susan's extract on the preceding page. This focus has two specific origins. Firstly, all the study wards used some form of the Roper, Logan and Tierney Activities of Living model of nursing to organise care, a model which focuses heavily on individual functional abilities (Roper et al. 1980). This was true of both medical and mental health settings. Secondly, the majority of patients had been admitted because of inability to meet self care needs or deficits in function. Many of those in long stay wards have been admitted because previous carers, either within

the home or in nursing homes, were unable to meet the patient's needs. While the origins of the focus on function are, therefore, easy to explain and the organisation of the wards allows it to be carried into practice with ease, the dominance of this focus is, nevertheless, overwhelming.

Through observation and in some interviews, the drive to improve or support functioning determined practice throughout the study field. This could be understood clearly at meal times when many patients were fed while others struggled to manipulate cutlery which they did not recognise. Some nurses were able to understand the problems experienced by their patients, making links between damage to the brain and difficulties in recognising cutlery and initiating feeding. Others saw the difficulties and gave assistance offering prompts and encouragement or, simply, a presence to ensure that courses were eaten in the correct order or foodstuffs were not inappropriately mixed. Finally, however, a number of nurses failed to link the dementia and the eating difficulties. They chose instead to leave patients to manage, or flounder, on their own with the stated aim of promoting independent functioning. When asked about this approach during observation periods, the nurses often responded with remarks about focussing on independent function in order that the individual could manage at home alone after discharge.

The focus on function can enhance an individual's independence but only in situations where account is taken of the features of dementia. Those nurses who related the pathology of dementing illness to the difficulties experienced by the patient could use simple strategies such as prompting or demonstration to enhance the individual's level of functioning. However, those who focussed on functional abilities without regard for underlying disease processes ran the risk of giving poor quality care which neither enhanced function nor promoted independence. Those nurses working in long stay wards also focussed on function but not with a view to enhancing independence, simply as a means of organising their workload.

Despite the overwhelming importance of this functional approach in shaping care practices, some of the most compassionate care observed during the study did not follow this pattern. Those nurses who spent time walking with a patient who chose to pace the corridor, or brushing a patient's hair in order to form a tangible link with a comforting aspect of that individual's past, did not focus on function. These nurses individualised their care but not through an assessment of what the individual could manage to do themselves but, rather, through an analysis of very personal biographical details. This approach to care will be discussed further in chapter six when discussing personhood.

5.7.4 Nurse/Patient Relationship

The final way in which the conceptualisation of dementia as disease had an impact on care practice was in shaping the nurse/patient relationship. This relationship was central to the study field, as outlined on diagram one, and forms the backdrop to the interactions observed during data collection. There were two related issues raised by nurses during data collection. Firstly, understanding the pathology underlying the symptoms exhibited by patients helps nurses to objectify the symptoms. This has the benefit of helping the nurse when challenged by the features of disease exhibited by the patient. Carol gave an example of this during an interview with her;

SJR: So how do you think that thinking about it as a disease would help the nurses to look after the patients? Is it mostly to do with stigma?

Carol: Well, if you've got someone who's repetitive all the time and they think it's just 'for God's sake!', where if you can explain to them the part of the brain that's involved, that it's the person's dementia, or because they've had some clot in some branch, then you can explain it more.

Carol: But if you can explain to someone, you know, it's like, you know if you cut off your ... (indicates fore arm) because you can't see someone's brain because it's not visible, but you can see 'oh, isn't it a shame. That hand doesn't move because of that injury' and it is

difficult to get that into certain people's brains because sometimes they think they're just being irritating (RN).

The nurses found that attributing symptoms to a disease process allowed them to feel less irritated by features of patients' dementia. Despite many nurses reporting during focus groups and interviews that they felt drained or irritated by constant repetition, shouting out or wandering, this did not reveal itself during the course of observation. However, the presence of a researcher may have altered the dynamics of the situation and observing practice only offers insights into what takes place in the ward area, rather than what the nurses feel at the time.

The second and related point raised by nurses was that of blame. The disease label serves to distance nurses and family members from the horrors of the apparent decline but it also shifts the perceived responsibility from the individual to the disease itself. An individual adult is considered, by society, to have control of his/her body. However, this responsibility is relinquished in varying degrees in the face of a disease over which an individual can be expected to have no control. Understanding dementia in terms of disease prevented the individual patient shouldering any blame for either the pathology or the resulting deficits and behaviours. With the possible exception of substance induced dementias which are rare in care of older people, dementia generally comes without reference to blame of an individual. While it would be professionally unacceptable as a nurse to blame a patient for having a specific diagnosis, the social world can be unforgiving in its attitude to disease. Stigma will be discussed more fully in chapter seven, however, society may comment on diagnoses which result from an individual's behaviour. For example, alcoholics may be refused transplants, a resource based decision which also carries a social message. Dementia, understood as a disease, carries no blame and neither do the symptoms of dementing illness. Maria and Carol both remark on this;

Carol: like, you remember the old chap that used to say ‘milk, paper, chocolate’?

SJR: Yes

Carol: Well, I was trying to say something and he’s already said that just three seconds ago. I mean he’s got no recall of having asked you for milk, paper and chocolate. And it, we all, even though you know it, we can still get irritated. But, at the end of the day it wasn’t his fault ‘cause he’s got an illness (RN).

Maria: You know. I mean, even the aggression side I can completely understand that that’s part of the dementia disease. It’s you know, you’re gonna get that with em, you know with the sort of ongoing process. I mean it’s an illness. It’s their illness and you just. I wouldn’t ever think oh you know so and so’s aggressive and you know, that’s not very nice or whatever.

SJR: Yes. You’re not blaming them. It’s not, it’s not their fault.

Maria: No not at all cause you can’t, you just can’t (MH).

These related points clearly show that conceptualising dementia as a disease affects the nurse/patient relationship by changing the view that the nurse has of the patient and their illness. Behaviour which is outwith social norms for interaction between two individuals can be excused on the grounds of disease. This reduces the challenge to the nurse of the features of dementia and helps the nurse to build a therapeutic relationship with his/her patient.

5.8 Conclusion

Dementia is conceptualised as a disease by a large number of nurses involved in this study. The medical model proved to be the dominant paradigm throughout the study field and was influential in shaping this conceptualisation. This model pervades both nurse education and practice and, along with structures of the workplaces, contributes significantly to the nurses’ understanding. The nurses’ focus on dementia

as a disease emerged consistently from the data and was a view which the nurses were able to discuss with sincere belief and considerable conviction.

Data about diagnostic process, authority and use of specific disease labels were presented. For a few nurses it was helpful to know the specific disease process involved but, for most of the participating nurses, this additional specific information added little to their understanding of the individual patient's condition. Some of the nurses demonstrated a lack of knowledge about specific dementing processes while others understood the conditions but suggested that they were unhelpful in determining the course of disease or individual presentations. Differences between nurses from mental health and medical care settings were evident in this regard. Nurses' views of disease were attached to the umbrella term of 'dementia' rather than to the specific diagnostic labels. This was a significant finding with far reaching implications in terms of other aspects of this conceptualisation and its relationship with care practices.

Conceptualising dementia as a disease allows nurses to discuss the potential for progression within a disease context. However, data about progression were surprisingly limited. Reasons for this were outlined. Some nurses chose not to consider the challenges which lie ahead of a newly diagnosed individual, while others were unaware of the potential extent of progression of dementia in older people. This lack of awareness was attributed, in part, to structural divisions which saw patients, with varying severity of symptoms, cared for in different care units. Other difficulties, such as the variable course of dementing illness, contributed to the limited discussion of progression. Finally, societal views of ageing and multi-pathology in older people may have reduced the perceived need for planning ahead in this group of patients.

The nurse is challenged in conceptualising dementia as disease by the limited treatment options available and the difficulties in predicting the course of disease with any certainty. Some nurses find these challenges too great and move away from the conceptualisation of dementia as disease preferring to consider it to be part of the ageing process or perhaps just a cluster of unconnected symptoms. These ideas will be discussed in subsequent chapters. A disease label sets features of dementia apart from those of 'normal' ageing. This has the beneficial effect of distancing the nurses from personal fears of developing dementia by ensuring that dementia is not seen as an inevitable part of ageing.

The use of language by nurses was an important aspect of the data presented in this chapter. The nurses demonstrated their power and status through the use of medical terminology, showing language to be a form of capital to be exchanged in the social world. They also used the language of disease to distance themselves from the personal face of dementia and the unpleasant symptoms displayed by patients.

Finally, this chapter has addressed ways in which conceptualising dementia as a disease relates to practice. Practicalities of ward organisation were discussed along with approaches to care and the nurses' overwhelming focus on function. The nurse/patient relationship was also shaped by understanding dementia in this way, as nurses were able to use the disease label to distance themselves from unpleasant features of their patients' presentations and attribute these features to the disease.

CHAPTER SIX

FORGOTTEN SHOPPING, LOST KEYS AND HEARTS WHICH FORGET TO BEAT

6.1 Introduction

This chapter considers the conceptualisation of dementia as a memory problem and explores the central role of memory in helping nurses to understand the many features of dementing illness. The chapter begins by discussing theoretical aspects of memory before going on to consider it in the context of dementia care. Memory will then be discussed as a means of conceptualising dementing illness and the implications of this conceptualisation for practice will be outlined. Thereafter, memory will be explored alongside the other symptoms that nurses encounter in their care of people with dementia and the implications of understanding dementia as a fragmented mixture of features will be considered. Theories of individualised nursing care and person-centred dementia care will be discussed, as well as the nurses' focus on function which is a dominant feature of their data on care practices.

6.2 Theoretical Aspects of Dementia

Memory is central to the data presented in this chapter and to the nurses' conceptualisation of dementia. The following section outlines some theoretical aspects of memory in order to provide some theoretical context for some of the discussion which follows throughout this chapter. Since the time of the ancient Greeks, academics have considered psychological aspects of memory and have sought to understand people and their behaviours by means of psychological

explanations. More recently, there has been an increased level of understanding of brain anatomy and it has become possible to pinpoint structures within the brain which contribute to the formation and management of memory. This developing knowledge has allowed progress to be made in neurosurgery and has offered new insights into the process of memory formation (Parkin 1999).

Memory is associated with the recall of past events, relationships and experiences. However, memory is required in order to understand apparently present events. For example, in order to read a single sentence the reader must hold in his/her head the early words in order to make sense of the remainder of the sentence. This use of memory in conscious mental processing was described by one of the first psychologists to explore the concept of memory, William James. Writing in the 1890s, James described primary memory as that required for awareness and processing and secondary memory as a more permanent knowledge store (James 1950). His ideas were largely ignored until the subject of memory was explored more fully in the 1960s and his terminology was replaced by the terms 'short and long term memory store' which are used in current psychological discussion.

6.2.1 Anatomy of Memory

The development of anatomical knowledge about memory has taken place in a rather haphazard fashion. Experimental surgery carried out on a young man in Montreal in 1953 attempted to cure intractable epilepsy by means of a temporal lobectomy. This surgery was successful in improving the epilepsy and allowing the remaining symptoms to be controlled by medication. However, the patient became profoundly amnesic with little awareness of current affairs, family members or new vocabulary. The patient's memory appeared seriously damaged by the surgery. A more detailed consideration showed that the patient did recall language and skills from the time prior to his surgery and could recall events from his childhood. This indicated that

memories stored prior to the surgery remained intact and that the memory required for processing language and conscious thought were also useable (Parkin 1993).

Anatomy of the brain is now well understood following experimental research and surgery but the specifics of function are more difficult to define. The functions of the brain are spatially distributed within the organ (Parkin 1993), with one function taking place across a range of structures. This adds to the complexity of exploration in this field, as it is only through damage to minute areas of the brain and subsequent study of the effects that conclusions can be drawn about function and anatomy. For example, damage to the hippocampus was widely understood to damage memory but it was only after the examination of a patient following a stroke, exclusively in the hippocampus region, that specific memory effects could be recorded. Hippocampal damage resulted in acute problems in remembering new information but no differences in recall of information acquired prior to the damage occurring (Parkin 1999). Further neuropsychological observations show that damage resulting from Korsakoff's disease and subsequent bleeding in the diencephalic regions and atrophy in the mamillary structures of the brain also impair memory and, consequently, implicate these regions in the processing of memory (Cermak 1979).

6.2.2 Formation and Organisation of Memory

Memory is organised into short term store and long term store. Short term store holds the memory required for functioning and conscious thought along with recent memories of events, conversations, experiences and words. Long term store is a complex filing system comprising three distinct types of memory – semantic, procedural and episodic memories. Semantic memory covers aspects of general knowledge and factual material while episodic memory encompasses personal experiences. These two types of memory are often grouped together as it is difficult to separate them effectively. For example, knowledge of the route from Edinburgh to London may be factual information which could be recalled or could result from

personal experience of the trip or a discussion about the journey. It may be possible to determine the origin of the memory but, in many cases, the origins overlap and the single term 'declarative' memory may be more appropriate. Procedural memories are not consciously accessible and involve processes or skills such as typing or playing the piano. In order to access information about the skill, it is necessary to replay the procedure in the mind in order to access the information. For example, it may not be possible to recall the position of letters on a keyboard but may be possible to type a name or word using that keyboard.

Memories enter short term store and are moved to long term store through a process known as consolidation. This process has variable time frames and may take up to 25 years (Parkin 1999). The process of transfer to the long term store is influenced by the form of the memory, shape, visual image, object or words. Rehearsal is also thought to influence the time required for transfer, as this process is thought to keep the memory in short term store for longer periods of time but may make recollection more intense because of the repetitive nature of the rehearsal process (Klatzky 1975).

6.2.3 Remembering and Forgetting

It is common to explain difficulties in recalling information in terms of memory failure or failure to retrieve a stored memory. However, that explanation assumes that all experiences are recorded in the brain and it is simply the method of retrieval which is at fault when something is forgotten. During the 1930s and 40s this idea was popular and was given more credence as psychologists observed trivial recollections from patients who underwent stimulation of the temporal lobes during surgical procedures. These patients recalled mundane facts rather than major life events, suggesting that every experience was recorded in memory. More recently, it has become clear that the recording of memories is selective rather than all embracing (Parkin 1999). The process of encoding the memory for storage in the brain determines the manner in which the event or experience will be recalled.

Meaning is important in encoding the memory. Events, words or experiences which are understood or which have meaning to the individual will be more readily stored than those which hold no meaning.

Remembering happens as a result of cues. It is a process of reconstruction rather than simple retrieval and involves a constructive process between present cues, fragments of stored information and, ultimately, a newly created image reflecting a past event (Schachter 1996). Scripts are used to help the process of remembering. These scripts form templates of the world based on past experiences and allow memories to be accessed. For example, when asked what you did this morning you will be aware of your normal morning routine – getting dressed, having breakfast, walking the dog – and will use these events as ‘triggers’ to help you remember that you returned home with the dog and went straight out to the swimming pool. The script is based on previous experiences and these experiences may lead to wide variations in scripts. This is clear when observing the memory of a toddler who makes improbable links, based on previous experiences. For example, when recalling this morning’s trip to the duck pond, the toddler reports that today there were no fire engines! The adults are confused as they do not link the duck pond with fire engines but a previous walk around the pond had coincided with a loud fire engine passing by and the toddler clearly linked the location with this experience and formed a ‘script’ accordingly. Scripts or schema can be both helpful and unhelpful as they can distort recall, either by limiting its scope or adding in assumptions based on past experiences.

Forgetting may happen because of retrieval failure, encoding problems or storage failure. Retrieval may fail because emotions do not allow it; for example, distress, anger or stress may block the retrieval. Freud would suggest that repression of memories would contribute greatly to this type of retrieval failure (Baddeley 1976). Context may also make retrieval impossible. Nurses may experience this when they meet someone who was familiar to them as a patient but is now encountered in their role as a car salesman or waitress. In this example, the context and the familiarity do

not link effectively and retrieval fails. Information which is poorly understood may be forgotten, as encoding is not accurate. Gestalt theory suggests that form and shape play an important role in the encoding system, with certain shapes being more readily encoded than others (Baddeley 1976). Storage problems could result from consolidation difficulties or loss in the long term memory store. Consolidation problems may occur through shock, intoxication or organic damage. Alternatively, new memories may displace previously learned information and cause it to be lost (Parkin 1999).

6.2.4 Lifespan and Memory

Memory changes occur at either end of the lifespan. Children recognise objects implicitly having seen them before. However, they may have poor explicit memory, which will make them unable to articulate that they know the object because they have seen it in the past. This implicit knowledge of objects, faces or experiences is present in young children although it is difficult to test. The development of explicit memory apparently increases during childhood and into adulthood. This is due to improvements in the retrieval systems, development of scripts or schema, as outlined earlier and increased capacity to store memories which develops over childhood. The increased capacity for explicit memory developed over childhood is mirrored by the decline in older people. Short term store is largely unchanged by age but the ability to explicitly recall information declines in older age. Implicit memory remains unaffected by increasing age (Parkin 1999). Ability to recall contextual information is particularly damaged by advancing years and this prevents recollection. Loss of neurones from the frontal lobes and hippocampus contribute to the memory declines and impaired processing speed makes the memory declines more apparent.

Memory is a complex and well documented area of study. This writing outlines some of the main aspects of memory organisation, storage and retrieval but is far from being an exhaustive account, omitting many of the more complex areas of research.

This writing is intended to provide some context for discussion of the nurses' data on memory. Memory problems are a well documented and recognised early symptom of dementia. Lay people as well as those working with people who have dementia are aware of these difficulties and the link between dementia and memory difficulties is well established. The following section outlines very briefly how memory difficulties may result from dementing illnesses.

6.2.5 Dementia and Memory

Human memory is an information processing system (Klatzky 1975). Information enters this processing system by means of one of the senses. Information is then recognized and sense is made of it. The information is then 'translated' from a sensory image – for example, a sound or visual image, into a meaningful shape or concept. It is then stored in the short term memory for further manipulation and use. In order for this process of recognition to take place it is necessary for an individual to attend to the sensory stimulus. This may mean picking it out of a number of other stimuli, focussing attention on that specific piece of information or simply having the capacity to recognise the information as important. This is often a challenge for an individual following stroke or in individuals with vascular dementia. In Alzheimer's Disease people can appear to function well as, in the early stages, they can perceive and make sense of the world around them. However, they can not process information in order to create explicit memories of their experiences. The brain of an individual suffering from Alzheimer's type dementia displays amyloid deposits which damage the medial temporal-diencephalic regions of the brain. These amyloid plaques prevent the individual from weaving together the range of information fragments which result from an experience – what is heard, seen or touched, what emotions are experienced and the thinking which takes place during the experience (Schachter 1996).

Semantic knowledge is commonly disturbed in Alzheimer's disease. Dissolution of knowledge about everyday objects, people and words gradually undermines general knowledge and understanding but is unrelated to concurrent declines in episodic memory. People living with Alzheimer's disease usually experience both types of impairment but those who have 'semantic dementia' experience the decline in semantic memory while episodic memory remains intact. They can, therefore, recall past experiences and events with both detail and accuracy whilst being unable to recognise everyday objects.

This theoretical section provides a backdrop to the nurses' data on memory. Bourdieu's work stresses the importance of context in making sense of experiences and interactions within the social world. Therefore, the theoretical outline given above sets the scene for the discussions of memory and dementia which follow. Within the context of academic writing, this format seems appropriate yet the utility of this theoretical knowledge is called into question by the nurses' data. Early analysis of the data showed that the nurses used lay understandings of memory in the focus groups and interviews. In view of Bourdieu's assertions that information can be understood differently in the fields of production and reception, discussed in more detail in chapter three, academic writings on memory were considered in order to ensure that my own limited knowledge of psychological research in the field of memory was not restricting the analysis of the nurses' data. No such restrictions were noted but the academic literature did provide a useful basis for the analysis, demonstrating that, despite apparently lacking theoretical foundations, the nurses often did recognise subtle differences in information processing and recall which they subsequently used in their care. Furthermore, taking Bourdieu's theories on production and reception a stage further, the presentation of analysis in this chapter could not be taken seriously in the field of academic reception with only some unclear musings about memories collected from discussions with the contributing nurses. The theoretical outline given, therefore, will form part of the ongoing discussion of data presented in this chapter.

6.3 Presentation of Data

Memory problems are often the first sign of dementia and for many are the only sign that anything is wrong during the early months or years of dementing illness. Memory problems such as short term memory loss and fluctuations in memory are often dominant and defining characteristics of dementia. Memory and dementia are linked by lay people which can lead to people suspecting a diagnosis of dementia when faced with memory difficulties. The masking of memory lapses in early dementia is common and people often go to considerable lengths to cover this feature of dementia. While social pressures, stigma and the need to appear competent all add to the desire to cover symptoms of memory loss, the unspoken connections between memory problems and dementia underpin the need to mask the early features of disease. The knowledge that the general population have of these connections can lead them to approach health professionals in the first instance. Strong connections between ideas about memory and dementia make it likely that memory should feature in the data generated by nurses. Given the strong connections outlined above and the emphasis given to memory in the pilot data, it is perhaps surprising that there is a relatively small body of data on memory from the nurses. This may indicate that there is an assumed understanding that dementia and memory go together, which prevented nurses from raising this topic in the focus groups or interviews. Furthermore, the lack of theoretical knowledge about memory means that nurses could not present themselves as theoretically knowledgeable during the data collection process. Discussion of mundane topics such as ‘forgetting’ could be seen to have less capital attached to them than more theoretically driven discussions.

The data generated by nurses regarding memory fall into two main areas. Firstly, some nurses conceptualised dementia in terms of memory and used ideas about memory to shape and explain other features of dementing illness and its place within the social world. A second group of nurses discussed memory problems as a feature of dementia and understood it, along with a number of other symptoms, to be part of the widely varying clinical presentation. Both of these uses of ideas about memory

will be discussed in the pages which follow and emerging issues relating to care practices will be highlighted.

6.4 Memory as a Way of Conceptualising Dementia

For many nurses, memory was the key to their conceptualisation of dementia. As outlined earlier, links between memory and dementia are often assumed and are readily understood by both professionals and lay people. As one of the earliest and most obvious features of dementia, memory problems are often at the forefront of people's thinking about dementia and the nurses contributing to this study were no different. Some of the nurses used memory as a way of explaining many of the features of dementia. For some, memory was the key to their understanding of the concept of dementia. Molly demonstrates this in her short statement;

Molly: It's a memory problem that they have... that's the whole thing.
It's a cognitive procedure that's gone wrong really (RN).

Molly uses her understanding of memory as the 'whole problem' to shape her view of other aspects of dementia. This was quite common in the study group, with many examples of this conceptualisation scattered throughout the data. Angela discussed the very practical aspects of finding the toilet in the following extract;

Angela: I think the tolerance levels get low when even teaching somebody that needs the toilet how to use a buzzer and then they end up being incontinent, just because they forget.

SJR: Incontinent yeah.

Angela: And families say but she's never incontinent. But then she knows where the toilet is at home and you know. It's a memory problem and that makes other problems, you know forgetting you

need, your bladder forgetting, forgetting where to go, forgetting the buzzer (RN).

Angela shows how incontinence is explained in terms of memory deficits. At one level her explanation demonstrates her understanding that practical issues such as an unfamiliar environment or not retaining information about how to get help might cause an individual to become incontinent. However, Angela's remarks also highlight her use of memory to explain aspects of incontinence which potentially result from cognitive damage. Explanations such as 'forgetting you need' and 'your bladder forgetting' suggest that the learned control of continence can simply be forgotten without considering the underlying neuropathology. Angela also touches on some of the frustrations felt by nurses who have to be repetitive in their interactions with this group of patients. This is a factor which will be discussed later in the chapter.

Other nurses take the conceptualisation of dementia as a memory problem further than Angela. For example, Flora suggests that swallow reflex loss can also be explained using the concept of memory;

SJR: So you probably wouldn't link swallow problems with dementia really?

Flora: No. But I mean, on saying that, they do forget to swallow. You've got to keep you eye.

SJR: Yeah some hold food in their mouth, but it's a reflex.

Flora: They hold food. And then they do forget to swallow because it's, the mind, it's the memory's starting to go and they don't remember to do it. (RN)

Flora uses memory to explain physical symptoms which result from damage to the brain. While the loss of a swallow reflex can not be explained in terms of memory, Flora is clear in her thinking. This shows the power of memory as a concept connected to dementia and shaping thinking on the subject. However, it also indicates some serious gaps in nurses' understandings of physiology and the autonomic aspects of the nervous system. This is a difficulty which is further exemplified by Emily's remarks;

SJR: Towards the end stages of dementia then people's brains are damaged in such a way that they can't any longer swallow and I wonder if nurses do link those 2 things... you know, link the confusion and forgetfulness that you've mentioned we understand is dementia with those symptoms that come about later on.

Emily: Yeah I mean, me personally I don't, but I mean, you do. Like we do assess our patients daily and that's the kind of thing you do pick up. I mean cause if one patient is yesterday managing fine but the following day you say oh there's something no right, that's when you sort of pick up on it. Initially, you don't link it. Initially you're sort of saying to yourself they're starting to go a bit poorer and then you look more into it and you'll say I'll refer them to the speech and language therapist cause they're forgetting to swallow. They are forgetting. Getting a bit more incontinent as well which is not normal. So what you do, you check them for a UTI. But in the end it all goes and their heart just forgets to beat too and that's that, all forgotten.

SJR: Mmmm.

Emily: Because like what I said, I mean dementia, you've no actually, there's no a sign, a guideline saying to you, you've got dementia, is there? It's all just forgotten like, slips away and that.

Emily's extract raises a number of points, not least the idea of the heart 'forgetting to beat' which was one of the most striking remarks made during data collection. Emily shows how, like Flora, she uses the concept of memory to explain and make sense of the deficits of advanced dementia, even when these ideas do not fit with basic physiological knowledge. These remarks may indicate gaps in knowledge on the part of the nurses or may point to memory simply being used as a device which helps

nurses to explain the patient's presentation. Both Flora and Emily appear firm in their belief that swallowing and heart beat are under conscious control and can, therefore, fall victim to an individual failing to remember to undertake the action at the correct moment. This points to a major misunderstanding of physiology which is gravely concerning. However, some nurses may be using memory as a means of making the complexities of human physiology more accessible to the lay population by using the metaphor of 'forgetting' to explain the presentation which results from cognitive damage. Whichever explanation might be true, the power of memory is potent as a means of conceptualising dementia and the resulting deficits.

Emily's remarks also demonstrate how nurses often look to physical causes and cures for deficits which become apparent. For example, swallowing problems result in referral to the speech and language specialist and incontinence results in investigation for urinary tract infection. While these courses of action are clinically appropriate, the emphasis placed on these approaches gives an insight into the way in which the nurses think about emerging issues. Finally, Emily mentioned daily review of each patient which leads to discussions of individualised care. A section dealing with individualised care will follow later in this chapter.

Steven suggests that memory problems are the defining feature of dementia for relatives but not for the individual themselves;

Steven: Well (sighs), I think it's [memory problems] the most important symptom, the whole deal, as far as relatives are concerned. The actual individual patients, doesn't realise that their memory is affected. They've got it in their head that there's something that they're supposed to be doing or somewhere they're supposed to be at that time and I supposed that the main symptom that affects them is more the kind of agitation or restlessness that they tend to suffer as a result of wandering around and being confused. Memory problems. It's how folks outside understand it, they can grasp it (MH).

Steven works in a long stay ward with patients who have little remaining insight into their symptoms. Many of the other contributing nurses care for patients who are acutely aware of their memory difficulties. However, Steven makes an interesting remark about the importance that family members place on memory difficulties as a defining feature of dementia. Memory problems are, Steven suggests, readily understood by family members and form a significant part of the lay person's understanding of dementia. Steven's insight is useful, as it sheds light on the way in which nurses may use links between memory and dementia in their interactions with family members. His awareness of relatives understanding dementia through ideas about memory suggests that this may shape his discussions with family members. The data collected from Flora, Emily and a number of other contributing nurses show the lay perception of dementia influencing the understanding of the nurses. However, this finding does not hold true for all of the nurses, with many other discourses influencing their views. Steven alludes to the concept of memory having more importance for 'folks outside' rather than for the nurses. For a number of the study nurses this suggestion seems reasonable with the influence of academic literature, the dominant medical model and disease processes, among other influences, being important contributors to their conceptualisation. However, many of the nurses did, as the data presented demonstrate, use the concept of memory to shape their understandings of dementia, combining lay and professional influences in their conceptualisation of dementia.

Bourdieu's writing stresses the importance of reflexivity at each stage of the research process. My personal and professional background influence the study at every stage. This was particularly true of the collection and analysis of the data. Chapter four outlined the way that the study was conducted and remarks were made about my own performance as a researcher and the influences which contributed to the study as it is presented in this thesis. The material presented in this chapter gave rise to a greater emotional response than much of the other data. This response started during data collection, continued through analysis and remains with me now at the time of writing. The issues which arise from the data started with the contribution from

Emily. Emily was an experienced nurse on a busy general medical ward. She was an enthusiastic contributor who was very keen to talk to me, as she stated that she knew a lot about dementia and felt that research in this area was important. She was also enthusiastic about contributing to research, albeit on a small scale, as she was keen to ensure that the study remained grounded in the practical reality of ward nursing. Emily had clear views and was happy to express them but my great disappointment was the data presented earlier in this chapter where Emily discussed memory being key to her understanding of dementia. I felt annoyed and disappointed that this nurse, who considered herself knowledgeable in this field, could really believe that human hearts ‘forget’ to beat. My feelings about the data must have influenced the dynamic of the interview although the transcripts do not show this to any great extent. Emily was generous with her time and her views and my remarks are not intended as a personal slight to a capable ward nurse. I simply felt disbelief that ideas about memory could be taken to this extreme.

By the time of analysis, it was clear that Emily was not alone in her understanding of dementia in terms of memory. Flora and many other nurses whom I encountered during observation alluded to memory determining the physical declines of dementia. The acute disappointment and irritation that I felt after my interview with Emily faded and I am left with disbelief and puzzlement as to how the nurses can conceptualise physical symptoms in terms of memory. For me, the personal experience of spending time with my grandmother during the course of her dementia was largely about memory and its erosion. Until the final months when many other difficulties emerged, memory problems were central to her experience of dementia and that of our family over the years that she lived with dementia. Despite the dominance of memory in my personal experience, I can not envisage ever considering that an individual may forget to tell her heart to beat. However, these views did not come from one nurse but from a number of nurses in a variety of clinical settings. In many cases, these were experienced nurses whom I observed running wards efficiently and who generously helped me with my study. The views expressed by the nurses clearly show one way in which nurses conceptualise

dementia. This may be a rather limited conceptualisation but the data demonstrate the importance of memory as a concept which shapes some nurses' understandings of dementia.

Not every nurse who conceptualised dementia in terms of memory took the conceptualisation to the extremes expressed in the section above. Indeed one of the most interesting things about the data on memory was the limitation of that data. Memory and dementia are so closely aligned by nurses as to make memory an assumed narrative. Therefore, in comparison to the pilot data, which were gathered exclusively from lay people, the study data included comparatively few references to memory. This may be because nurses have other ways of considering dementia alongside the lay vision which may focus more exclusively on memory. For example, this work has found nurses who draw on models of disease, notions of journey, experiences working with patients and families and also workplace structures in shaping their thinking about dementia. Among the nurses who conceptualise dementia as a memory problem were the group, introduced already, who linked all aspects of dementia to memory and considered each feature in this regard; for example, hearts 'forgetting' to beat and patients 'forgetting' to swallow food. Further to this group, however, were a group of nurses who considered memory deficits to encapsulate the whole meaning of dementia but who were limited in their vision. These nurses did not consider memory problems to be one among many features of dementia in the way that many nurses who will be introduced later in the chapter did. They did consider memory problems to be 'the whole problem' and did not link any other symptoms with the memory problems, choosing to consider these to be separate and unrelated difficulties. An extract from Pete clarifies this point of view;

SJR: So what do you think when you're working here in this rehab setting? What do you think when you're told one of your patients, the next new admission, is going to have dementia?

Pete: To be honest it's not a thing that I really think, simply because it's not an unusual thing. It's not unusual to hear Mr so and so's coming down. He has his CVA. He's had a history of dementia for 2 years. That's not an unusual thing. Em, in fact, probably the majority, there's some degree of senility or dementia there. So I don't think much about it and you just take it as you find it.

SJR: So what would you expect if you were told that Mr whatever his name has dementia? What does dementia mean to you?

Pete: This patient is demented or has a degree of dementia and you go and talk to them and you think where did they get that from? Who assessed that patient? Cause you actually find. They may be forgetting from time to time em, but to put it down as a degree of dementia you know...bit drastic.

SJR: So, so if you say somebody's forgetful, that's not the same as dementia?

Pete: No. I'm forgetful, but I don't have dementia, I think (laughs).

SJR: Yeah ok. So there has to be more to it than, just forgetfulness?

Pete: Oh yes.

SJR: But what other kind of things could there be? (pause) Or is it just that they're forgetful a lot of the time?

Pete: Well. No no no no no. It goes beyond. Certainly to be forgetful, but it would be an extreme I think, and maybe to an extent, inappropriate behaviour because they don't really understand what they're doing. They forgot already what they've done. So again em, take that as it comes. Treat them individually. It's all about forgetting but not just normal forgetting, really severe forgetting.(RN)

This lengthy extract from Pete's interview shows how he worked through his thoughts about dementia during the course of the interview. Despite considering there to be more to dementia than memory problems, he could only conceptualise dementia in terms of forgetting. He drew a distinction between the memory slips which he himself has and the pathology of dementia but encapsulated the whole meaning of dementia in ideas about memory and forgetting. His contribution was not a simple or poorly thought through response. The extract shows Pete thinking about the meaning of dementia before responding in the interview. His difficulties were

also clearly evident in many of his colleagues and may indicate a lack of knowledge about memory. Angela also highlights the importance of memory in her understanding.

Angela: [when they are in hospital] the older person's memory's taxed. Well my understanding of dementia is because they cannae learn something new, they've forgotten how. So hospital, that's them learning something new. Where the toilet is, what the daily routine is you know and things like that, and who we all are.

SJR: Yeah it's a lot to take in.

Angela: It's a lot to take in when they've never had to tax theirself. They even watch the same television programmes. Coronation Street, Take the High Road and nothing changes.

SJR: That's right. So, coming into hospital and learning new things is one problem

Angela: I think it is, but its all forgetting, taxing the memory. Well that's my understanding.

SJR: but what other symptoms do you see; other things that you think are important?

Angela: Well they find it hard to interact with other patients and staff and things. Especially people that are not demented and they're up-to-date. Because I mean often dementia people live in the past so they're you know, they're no orientated to time and place and any topical things that are going on in the world. They find it hard cos they forget all that.... they kind of get left oot because they cannae participate in conversations. (RN)

Both Pete and Angela's responses highlight the dominance of memory as a means of conceptualising dementia, demonstrating how other difficulties are understood and explained in terms of memory. However, both also demonstrate their inability to fully explain aspects of memory. The literature discussed in the early pages of this chapter contains fundamental information about memory which was not raised by any of the contributing nurses. Indeed the data collected show little evidence of any theoretical awareness of memory on the part of the nurses. Data presented earlier in

the chapter demonstrate that some of the connections made by nurses had little grounding in fact. For example, the nurse who describes a patient who ‘forgets’ to swallow shows little understanding of the swallow reflex. Knowledge gaps may, therefore, account for some of the difficulties that nurses have in making accurate links and in fully explaining their understanding of memory and dementia.

Pete’s remarks also highlight some language issues which were common, both during formal data collection and observation. Bourdieu stresses the importance of language in transmitting messages about a field, allowing insight into the habitus and dynamics which shape the field. Two phrases were particularly interesting and commonly used. These were ‘he’s had a history of dementia for 2 years’ and ‘there’s some degree of dementia’. These phrases always puzzle me as I cannot connect them to my own understanding of dementia. However, they make more sense if considering dementia as an extreme memory problem. For example, having a history of memory difficulties for two years makes sense as part of a clinical handover, while the process of living with dementia is more difficult to understand in terms of history. Also describing memory problems in terms of degrees is more readily understood than discussing dementia in those terms, as dementia is a clinical syndrome including so many different features and symptoms. These phrases or similar uses of language were repeated to me many times during the data collection phase of the study. They stood out as they indicated to me that the nurses’ understandings differed from my own. Within the general medical wards, this type of language is part of the culture of the setting. Medical histories are handed over as part of the medical model which shapes the working of the setting and the language used in this exchange of information is carried into discussions about dementia. A two year history of diabetes or depression might sound reasonable where a two year history of dementia sounds a little bizarre. The nurses’ use of language does not make any direct statement about their conceptualisation of dementia but the language does sound more comfortable when used against a backdrop of memory as a key feature of dementing illness.

This section has discussed nurses who conceptualise dementia in terms of memory. Academic literature about memory was outlined in order to set the scene for discussion of memory and ensure that the data from nurses were thoroughly interrogated. Thereafter, data were presented from nurses who understood dementia to be predominantly or exclusively a memory problem. Some of these nurses used their vision of dementia as a memory problem to explain other physical symptoms, attaching features of memory to other organs; for example, hearts forgetting to beat and patients forgetting to swallow food. Some data suggested that conceptualising dementia in terms of memory may be beneficial in discussing dementia with relatives, while others used memory to guide their own understandings of dementia and explain features and symptoms that they witness in their practice. A number of nurses considered dementia to be more than the simple memory slips of which we are all aware in our daily lives but still identified memory as the key component of their conceptualisation.

This chapter now moves away from those nurses who considered memory to be the single key focus of their conceptualisation of dementia and moves on to discuss those nurses who understand dementia to be a series of unconnected symptoms. Many of these nurses consider memory to be one among the many symptoms encountered when caring for dementia patients. Data will be presented in support of these varied and, at times, fragmented views of dementia. Following the presentation of data, the chapter will move on to consider the implications that these conceptualisations have for care practice. Individualised and person-centred care will dominate these discussions as they did the data on care practices. In addition, sections on risk and the nurses' focus on function will be related to the data presented throughout the chapter.

6.5 Memory as One Among Many Features of Dementia

Some of the nurses discussed memory problems as a feature of dementia and not as a means of conceptualising the dementing process. In some cases, this approach made

light of a distressing and potentially debilitating feature of disease. For example, Leanne compared patients' symptoms with her own absent mindedness;

SJR: So if you're thinking about dementia at a kind of personal level first, how would you think about it? What would come to mind?

Leanne: Personally it's like forgetfulness. I mean, I do it myself and I know I'm not demented, but you know, you put something down and then you go back and it's no there at all. (RN)

This approach seems to trivialise the memory aspects of dementia and may reflect a lack of insight into other aspects of the condition and its progression. Analysis of data presented in chapter seven indicates reluctance on the part of some nurses to consider the wider impact of dementia on the individual. Leanne's response may be an example of this reluctance and may serve to protect her and nurses like her from some of the greater horrors of the diagnosis. This is a topic discussed in more detail in chapter seven. While Leanne's approach can be seen to trivialise memory problems, some colleagues also discussed memory problems as a significant feature of dementia, rather than as a way of understanding the subject as a whole. Alison suggested that memory loss was one of the main issues endured by patients;

Alison: Memory loss. They don't know where they are. They're totally disorientated. They're back to their childhood and looking for their mum and dad and what have you. Eh, they want to get home to feed the kids. They need to get the kids ready for school... They kind of forget their sequencing

SJR: And memory's the biggest one symptom.

Alison: I would say so yeah. (RN)

Alison's account highlights some of the distress attached to forgetting which stage of life is current and what one's role should be. Alison's use of short phrases, repeated

examples and the non verbal emphases which she placed on her words, demonstrates the importance she attaches to an understanding of the disorientation which she links with memory loss. This insistence is more clearly evident on the recording of this interview. Alison understands memory to be a feature of dementing illness and while she does not use it to shape her understanding of dementia as a whole, she considers it to be a serious aspect of dementing illness. This view is in direct contrast to Leanne's view which assumes memory problems to be part of everyday life. It also contrasts with the view of Carrie in the extract below;

Carrie: Memory, yes that's bad news, it goes down the river. Mucks up your life, you know. Makes it all a struggle. Struggle with shopping and forgetting, forgetting your shopping list, buying the wrong stuff. You can't manage to cook it anyway, 'cause you've forgotten that and all... eh you struggle to remember the bus home and then find you can't get in 'cause you've forgotten your keys for the front door, you know. It's all a struggle for them. Nothing that serious each thing but makes life a struggle, a nuisance, you know what I mean? Everything gets forgotten and you can't get on like before. It's a pain for them and for the families ... mostly for them 'cause you'd feel daft yourself. A right pain. Guess there's more to it too eh, but it's mostly a pain. (RN)

The extracts presented above show nurses who understand memory to be a feature of dementia but do not use it to shape understanding of dementia more widely. They recognise memory problems to be one among many features of dementia. These nurses do not agree about the seriousness of the symptoms, with Leanne and Carrie both portraying the slightly trivial side of the memory deficits such as forgotten shopping lists and door keys. Alison, however, stresses the significance of the same deficits. Trivialising the deficits which result from memory problems may serve to lessen the significance of the dementia label in the eyes of the nurses. The examples given by the nurses in these extracts are not portrayed as significantly lessening personal agency in a life changing way. While inability to shop effectively may ultimately result in significant difficulties with independent living, the nurses give their examples in a trivial way. However, the same memory problems which cause

the practical inconveniences outlined by Carrie may also go on to erode decision making capability and damage independence. Within the social world, the capital attached to the successful use of a shopping list is considerably less than that attached to the management of personal finances. An individual who requires assistance with shopping does not, therefore, lose position within the social structure as much as someone who is no longer able to manage their own personal and financial affairs. By offering relatively trivial examples, the nurses portray the memory difficulties causing the minimum of social impact. These observations do not take account of the terrible personal distress which can result from the loss of any independence, however trivial the loss may appear to the outside world. However, they may shed some light on the motivations of the nurses in making their remarks.

6.5.1 Memory Problems and Blame

A second issue which emerges from the data about memory as a feature of dementia is that of blame. Each of us has had experience of forgetting things and we often consider ourselves to be silly or careless when this happens. Forgetting things can be frustrating and is viewed negatively. As a result, it may follow that an element of blame is attached to forgetfulness or memory problems. In chapter five data suggested that nurses deflected this blame from their patients by conceptualising dementia as a disease which, in turn, was blamed for the unpleasant or frustrating symptoms. However, some nurses made remarks during data collection which demonstrated that some did apportion some blame to the patients, albeit tacitly. The following extracts demonstrate this;

Andrea: I think it's difficult to look after dementia patients in a medical ward, when you've got people who're ill. And obviously the people with dementia, they need a lot of time as well and they do get sort of pushed to the side a bit, you know because you think, well at the minute this ill patient's our priority. You know, so you sort of have to say to the dementia patient 'I'll come back'. And it is difficult because they, they can't really... (interrupted)

Margaret: They don't listen!

Andrea: They don't really understand that it's because somebody's ill that you're not talking to them or not doing something with them.

Margaret: They usually do understand. They just don't listen or forget what you say. They don't listen! (RN)

SJR: Or do you think they [other nurses] think it's more of a memory problem?

Flora: Memory, memory and behavioural.

SJR: Memory and behavioural?

Flora: And behavioural aye. I think some dae think that, aye. I mean I never used to, and I still dinnae see it as that though.

SJR: What kind of things are behavioural?

Flora: Like, one man in particular was really aggressive with dementia. Em, and he used to run a wheelchair at the back of your legs when you were passing. We didnae come here to do this kind of nursing you know. We're here for stroke or general patients. We're no here to take that, any kind of abuse or anything like that. A lot of it's against themselves tae. Like one woman the now won't eat, turned her face tae the wall. Winnae swallow the stuff. Just being difficult but it's, she's going down. Really behavioural. Sometimes she eats but there's, you cannae tell when she will or if she's no gonna bother... forgets what she's doing and tips it everywhere. Uuh. Another one asks the same thing over and over. Just senile, forgetful but nippy like. Does it more when it's busy and you cannae think. That's behavioural too, ken? (RN)

Both Margaret and Flora blamed their patients for repeating things or not paying attention to what is said to them. Flora's description of a patient who was unable to manage food was distressing to listen to and showed how little some nurses understand about dementia and its many features. The blame attached by some nurses to their patients mainly resulted from the repetitive nature of their interactions with patients. The memory deficits and agitation displayed by patients led to

frustration among some nurses. One nurse made the following remark during data collection;

And then if you've 2 or 3 patients that are like goldfish that keep repeating themselves it does get a bit repetitive. And the other patients get upset because they hear this, 24 hours a day. Well, at the moment I'm going to have to transfer one of the patients [Patient A] out of one of my bays because this other patient's been in and ranting and rummaging in her stuff. She's [Patient A] not at that stage. She's actually quite bright and orientated. We're going to have to take her out, and put somebody else in that we know'll probably not even notice, cause they're just the same. Out of it. It's not fair but, for the patient that's got all her marbles there... she might complain (RN)

This extract has challenged me as a researcher, as my personal reaction to the tone and the content has been that of outrage! Indeed, the pseudonym of the nurse has not been used in this extract in order to preserve the identity of this nurse who has contributed other data used in this thesis. However, while no excuses are made for her remarks or the tone in which they are made, the structural difficulties which she raises are common to a number of the nurses' data. The repetitive nature of nursing dementia patients is commonly regarded as being stressful (Alzheimer's Scotland: Action on Dementia 2008; Edvardsson et al. 2009). This is made more stressful by the often conflicting demands of dementia patients, some of whom may be wandering or asking repetitive questions and other patients who are acutely physically unwell. These conflicting demands were mentioned by a number of nurses working in medical areas during the data collection. Furthermore, during observation it was clear that nurses were stretched by trying to care for patients with very different nursing needs. During observation on a busy morning shift, a patient had a cardiac arrest and the cardiac arrest team were summoned to the ward. The team and a large arrest trolley arrived on the ward and were impeded in reaching the patient by two individuals wandering in the corridor. One of these men repeatedly went behind the curtains where the arrest procedure was underway, creating a situation which was stressful for both the nurses and patients involved. The structures of the field of

inpatient dementia care contributed to some of the difficulties faced by the nurses. For example, in some of the study wards there were patients who were 'blocking' beds for weeks or months. These were patients who were fit to move from the ward but their destination could not accept them for a number of reasons, such as funding problems, awaiting packages of care, awaiting a bed in another unit or awaiting social work review. These structural issues led to stress on the part of staff and patients remaining in unsuitable accommodation for long periods of time. These issues are recognised in the literature to cause staff stress (Edberg et al. 2008). While these factors do not excuse the blame which nurses attached to patients for their memory problems, they do, perhaps, explain some of the underlying strains and frustrations which nurses feel.

The negative statements about patients and their memory deficits were restricted to the nurses working in medical settings and no such data was collected from those in mental health settings. This may be for a number of reasons. Firstly, the mental health areas were predominantly assessment or long stay units, with large numbers of dementia patients. Staff had chosen to work in these units and expected repetitive behaviour from their patients. Furthermore, the staff did not have the competing challenges of physically unwell patients in the same ward, although the staffing levels were poor which did leave nurses overstretched. Secondly, the culture of the mental health settings was quite different to that of the general ward. Within the ward, the habitus emerges from the cultures and traditions of the setting, interaction of individuals within the ward and the structures of the setting. For example, the mental health wards were structurally different from the medical wards in ways which were outlined in more detail in chapter four. The locked environment, lack of nurses' uniforms and more tightly structured routine in the long stay units influenced the habitus of the wards. Expectations of the ward and the patients within that ward also related to the ward dynamic. For example, unexpected loud shouting and patients who chose to crawl on the floor were two features of the ward which shocked me on my first visit to a mental health long stay unit. The mental health nurses were not shocked by these unexpected behaviours. Indeed, they were not

shocked by patients behaving in manners which were different to the social norms. This may be due to their expectations of people and their vision of what is appropriate in the care setting. These aspects of habitus set the general and mental health nurses apart and may, in some part, account for their different reactions to repetitive patients.

6.5.2 One Among Many Symptoms

Many of the nurses who contributed to this study said that it was impossible to conceptualise dementia as a single entity because of the wide range of seemingly unconnected symptoms and presentations. This was the case for nurses who demonstrated a wide knowledge of dementing conditions, as well as those who had more limited awareness. The wide range of patient experiences and presentations challenged even the nurses who cared exclusively for dementia patients. For example, Steven describes the wide range of presentations which he has come across in his practice;

SJR: Do you think nurses understand all the different symptoms that can be apparent in dementia or?

Steven: No. I think we're a long way from that because em, each patient is different and their presentation of dementia is completely different. Just like it is in the human population outside, people react to different situations differently. When people are in a state of dementia, there's different things that each individual will retain. For some people it's maybe, words or phrases from their job or from their life that they had in the past and it's different for each individual. So I don't think that nurses have by any means got all the answers to understanding everything. I think that we just, we go by a number of principles in text books about how to deal with it generally but a lot of your care is actually individualised towards that person and their individual needs are taken into account. And sometimes there's points where you have to maybe bend the policies slightly to adapt for the fact that an individual patient has a particular need that just doesn't fit with the policies that you have for caring for them. You have to do something else. You have to be a bit more imaginative. (MH)

Steven's views were almost universally upheld by nurses from both mental health and general backgrounds. Pete also stressed the individuality of the presentations and how this related to the treatment which they need.

Pete: It's very difficult and there's never really a right or a wrong answer I've found with dementia anyway. Cause what's right for this patient isn't right for this patient. I mean and I haven't read that much on dementia but it always seems to be kind of vague because it's a vague kind of thing. It's not like this guy's got a broken femur and this guy's got a broken femur and their treatment's the same. You have to really open the door up to dementia you know. Em, the only real experience I've personally had from dementia is when I worked in a dementia unit for a year. You know you had to be very open about how you treated this patient, how you treated that cause they were all completely different. Even from agitation one patient would be easily agitated by what you felt was quite a minor thing and the other ones were quite happy to sit there and hardly even speak. So I just felt that with dementia you really have to open em, the gates up em, and just see what happens with dementia patients. (RN)

Pete emphasises the need for individual approaches to treatment in dementia care. While individualised care will be discussed further in the following paragraphs it is also worth considering briefly some of the treatments which may be required. For example, an individual may be on a range of treatments for agitation, sleeping problems, memory enhancement or incontinence, to name only a few. The treatment of each symptom in isolation adds to the difficulty in conceptualising dementia as a whole. The fragmented treatment which meets the needs of individuals also contributes to the difficulty in compiling an overall view. The individuality of the presentation leads to an almost universal call for individualised care to meet the needs of patients. The environment is also recognised to play a part in the individual's presentation, a factor pointed out by Lauren;

Lauren: ... even telling somebody in a college or university oh dementia's this and this is how they lose all quality of their speech

and mobility, you haven't, you can't comprehend until you work and see.

SJR: Yeah, exactly what it might look like.

Lauren: And how it can, it doesn't follow a set path. They're all individual patients and they can have the exact same diagnosis but still present differently.

SJR: Does that make it difficult then to, to think about how you're going to look after patients because there's not a set pattern? You know you can't pull the book off the shelf and say yes, this is the way to do it.

Lauren: Yes I think, I think it does, yes. When you're getting a patient in and, you've been given so much information and they come in and they can present totally differently because they're in different surroundings. ... So yes. It's very challenging at times. (MH)

Memory problems were considered to be one among many other features of dementia. Despite common diagnoses, patients were expected to behave differently and have variations in their levels of agitation, understanding and memory. Aggression was mentioned by a number of nurses and, once again, wide variations in the triggers of aggressive incidents were expected by nurses. The expectation of wide variations between patients undermined the nurses' ability or desire to conceptualise dementia in a single way. For many, the range of presentations and potential symptoms made the understanding of dementia as a specific entity very challenging. However, for some nurses, the rhetoric of individualised care covered limited knowledge about dementia. Probing showed gaps in knowledge about potential features of dementia and showed many symptoms to be largely unconnected by nurses. For example, incontinence was often considered to be an additional and unexpected problem rather than a potential dementia related feature. Similarly, difficulties with gait or spatial awareness were rarely considered alongside the memory problems, as part of a clinical syndrome.

6.5.3 Caring for Individuals

Individualised care is recognised as good practice in nursing. Person-centred dementia care is also recognised as good practice in that field. Capital within the field of inpatient dementia care comes from the individual assessment and treatment of patients. Life story books and reminiscence sessions seek to reacquaint individuals with their personal history and with the history of their lifetime. Nurse – patient relationships are developed on the basis of individual approaches for each patient. The affirmation of the individual's sense of self through individualised care is of paramount importance with this group of patients. Within nursing more widely individually planned care is usually considered to be the best way to meet individual needs.

None of the contributing nurses mentioned person-centred care despite its dominance in dementia literature. However, a large number of nurses did make reference to what they called 'individualised care'. This is more reflective of general nursing literature than dementia literature. The reason behind the nurses' use of the phrases is unclear. Some may have considered the phrases synonymous, while others may have used the language of nursing rather than dementia care more generally. This is be one occasion where language can be used to tacitly denote belonging to a particular group. The nurses reflect their own professional group and academic base in their use of the terminology. The dementia literature does not always coincide with the nursing literature base, with a wide range of journals carrying dementia related material. For example, dementia research could be discussed in journals relating to nursing, social care, sociology, psychology, neurology or dementia specifically. Nurses working in clinical areas which focus on the care of a range of patients and conditions may choose to peruse those nursing journals which have wider appeal and a broader range of topics. These differences in academic base may contribute to the focus on 'individualised care' at the expense of 'person-centred care' which was originally discussed in terms of dementia care. The nurses did agree on the need to treat each individual differently and use that person's circumstances and personal

network to address care needs. Furthermore, the nurses recognised the need for different approaches to care, particularly when faced with challenging behaviour.

The dominance of individual approaches to care within the study field means that contributing nurses may have chosen to use the rhetoric of individualised care to portray a high quality service. In many areas, particularly the long stay settings, the care was not very individual, with 'comfort rounds' at regular intervals to ensure that everyone was regularly taken to the toilet and regimented mealtimes which ensured that patients were fed in shifts in order that each one could be assisted by a nurse. These wards had both the most individual and the least individual care practices. Patients' rooms were personally decorated with their own linen, photos and home comforts. Individuals' likes and dislikes were well known. They had their own clothes and were spoken to in a personal way by staff who knew each of them well. In contrast to this, the set times for trips to the toilet, sleeping and eating, rotas for bathing and outings were imposed by the structures of the ward organisation. In contrast, many of the more acute areas had patients dressed in hospital garments, sleeping in large shared bays and with a name above the bed often being the only point of reference for staff interacting with patients. These patients were regularly offered more choice in what and when they ate, when to bath or go to bed. Both sets of nurses considered themselves to be giving individualised care and, in some ways their assertions were true. However, it was clear during observation which care regime better met the needs of the individuals who were being cared for. While improvements could be made in any setting, the long term care wards all met the needs of their patients more personally than the acute wards. Given the structural and organisational aspects of the acute sector this was an almost inevitable outcome as the aims and lengths of admission in each care setting were so different.

Individual care is a powerful discourse which influences nurses in their care of patients with dementia and in their conceptualisation. While many nurses recognised the need for individualised care in the face of wide variations in their patient's

presentations, others used the language of individuality to cover gaps in their knowledge of general trends in dementia care. Nurses from a range of clinical settings purported to be giving individualised care, although this care looked very different. These differences may relate to qualitative differences between individualised care and person-centred care, as described in the literature.

6.5.4 Focus on Function

As discussed in the previous chapter, nurses had a tendency to focus on the functional abilities of their patients. This was as true for those who conceptualised dementia in terms of memory, as with any other group. Memory was related to function by the nurses who often considered memory impairment to be the root cause of functional difficulties. For example, during observation of a morning shift, nurses often remarked that certain patients needed prompting with self care tasks. These patients were able to wash and dress themselves but benefited from a having someone to remind them about what to do whenever necessary. The nurses explained that this was because patients tended to forget and focussed on this when discussing the patient's care needs.

Aspects of memory were used in the assessment of an individual patient's functional ability, with specific reference to risk and risk assessment. The law is one of the eight factors identified as being key influences in shaping the social world in which we live (diagram three). Litigation now plays a much more dominant role in nursing than in the past and this has influenced practice. Nurses now undertake risk assessments regularly and take steps to mitigate risk wherever possible. This is a particular focus in dementia care, where individual autonomy and risk become thorny issues. During observation, it was clear that memory and function were key features of the risk assessments carried out in the clinical areas. For example, functional assessments of mobility determined the type of walking aid required by an individual and the level of nursing supervision necessary. However, memory became

an important feature of the risk assessment, as it often became clear that individual patients did not remember to ask for assistance or to use the walking aids required. The falls risk assessments which were undertaken in most of the study wards took into account both pure function and memory. The documentation usually had the word 'dementia' noted by way of explanation for the memory difficulties included in the assessment.

Risk and its assessment have become dominant features of healthcare, as in many other areas of society. It is a powerful influence on the structures and organisation of nursing care. Staffing can be increased or reduced on the basis of patient risk assessments. Equipment can be purchased or denied in the light of identified risks. The whole nature of clinical settings can be changed by the locking of a ward door or the locking of bedrooms during the day, all on the basis of risk. In the day to day care of patients the focus on risk has increased the focus on function. Functional assessment and the documentation of patient function are used as the proof of nurses' knowledge and care of their patients. In turn, these assessments are used to determine risk and the measures taken to mitigate risk. Memory deficits are often highlighted as key features of these risk assessments and are often documented, by way of explanation, for falls, episodes of wandering off the ward or violence and aggression.

The nurses discussed in this section have considered memory problems to be one among many features of dementia. The range of symptoms challenged the nurses in their conceptualisation of dementia as a single idea. Some symptoms were not connected by nurses, perhaps because of limited knowledge or individual symptom treatment. Subsequently, the range of presentations among patients with similar diagnoses raised further challenges and led to discussion of individualised care. While individualised care is recognised as good nursing practice, the manner in which it is carried out may vary between clinical settings. Person-centred dementia care is a dominant feature of the dementia literature but was not mentioned by nurses contributing to this study although it may help to explain some of the differences

between care in the long stay and acute settings. Individualised care was considered as rhetoric which may disguise some gaps in the nurses' knowledge about general trends in dementia care. Finally, the nurses' focus on function was again discussed with reference to memory and the assessment of risk.

6.6 Conclusion

This chapter has considered the conceptualisation of dementia in terms of memory. The chapter began with an introduction to some of the theory surrounding memory. While this theory did not feature specifically in the data, it provided important academic context for the data generated from contributing nurses. Rather surprisingly, there were less data about memory than might have been expected. This was discussed in relation to the nurses' assumed understandings and also their wish to portray more specialist knowledge, rather than lay perspectives of dementia. The chapter then moved on to present the data which were split into two main categories. Firstly, memory was considered as a means of conceptualising dementia. These data demonstrated the way that some nurses understand all aspects of dementing illness in terms of memory. In some cases, this reached extremes with a number of nurses explicitly connecting physical deficits with memory problems. My own personal responses to these data were included. Thereafter data were presented in support of a second way of understanding memory, as one among many features of dementia. These data demonstrated the nurses' feelings about memory problems, with some stressing the serious and distressing nature of this feature of dementia while others trivialised memory deficits. Some of their motivations were discussed. Blame was also discussed, with some nurses blaming their patients for memory lapses and repetitiveness. The distasteful nature of these data was reflected upon. The fragmented conceptualisation of dementia, which results from understanding it as a collection of different symptoms, was highlighted. The range of diagnoses, varied presentations and different courses of disease all contribute to this difficulty in forming an overall view. These remarks led to the discussion of individual and person-centred care which were considered, by nurses, to be the best way to respond

to the variety of dementia presentations. Aspects of memory were key to the implementation of these forms of care and shaped care practices in the clinical settings. The nurses' focus on function and reflections on risk and risk assessment were also presented with reference to memory.

CHAPTER SEVEN

CONFUSION – TRAGIC SYMPTOM OR USEFUL DEFENCE?

7.1 Introduction

“With ruin upon ruin, rout on rout, Confusion worse confounded
(Milton 1667)”

From historic literary connections between destruction and confusion to humorous comic book portrayals of muddle and farce, the term ‘confusion’ is widely understood in the social world. This chapter explores ways in which nurses use ideas about confusion to contribute to their conceptualisation of dementia. Used by nurses from a variety of clinical areas, confusion emerged from the data, both as an important way of describing features of dementia and of conceptualising dementing illness more widely. It was also used as a device to avoid use of the term ‘dementia’ and to illustrate practical implications of dementing illness in care settings. These issues will be explored further in the pages which follow. The term ‘confusion’ itself requires little initial explanation, as readers enjoy their own understanding of the word from frequent everyday use. Analysis of the data did not indicate that any further specific definitions would be useful or that the term ‘confusion’ could be placed within a social context with any great utility. However, during analysis some common usages of the word ‘confusion’ were identified in the nurses’ responses. As a nurse myself, these responses were readily understood and were initially unquestioned. As data collection continued, the frequently used phrase ‘pleasantly confused’ became the focus of much analysis. Guided by Bourdieu’s thinking, the

context for the use of this phrase and the motivations underlying its use were explored, along with my own innate understanding of the terminology. These findings and literature underpinning these findings, will be presented alongside the data later in this chapter.

7.2 Confusion and Dementia

Nurses related confusion and dementia in two main ways during the course of data collection. Firstly, some nurses considered confusion to be an important feature of dementia. It was the first thing that many nurses thought of when asked about dementia and was one of the dominant concerns for nurses discussing aspects of care. Secondly, nurses contrasted confusion and dementia as diagnostic labels. A number of nurses recognised differences between confusion and dementia while others considered these labels synonymous. Some nurses chose to use different terminology in interaction with different actors within the field. For example, using the term ‘dementia’ when talking to colleagues and using the word ‘confusion’ when talking to patients or relatives. These two ways of considering confusion and dementia, together with the factors thought to motivate them, will be discussed in this chapter. Confusion will first be considered as an important feature of dementia.

7.2.1 An Important Feature of Dementia

When asked for initial thoughts about dementia, many of the nurses responded by talking about dementia in terms of confusion. Confusion was used by respondents as a term which would immediately encapsulate what dementia means. The first focus group demonstrated this;

SJR: What are your ideas about what dementia means?

Helen: Usually somebody who’s confused ...

Others: Yeh, that's it. (RN)

Helen's response was followed by silence within the focus group as participants appeared to consider her response to be adequate explanation. This very short extract does not fully demonstrate the certainty with which the response was delivered, nor the nodding agreement of colleagues around the table which served as an unspoken challenge to me as group facilitator. An extract from my notes taken after the focus group highlights my discomfort during the early moments of this first group.

Helen challenged me to disagree with her assessment that dementia usually means a confused person. She took the lead and gave a short and confident answer glancing round the table to receive the silent support of her colleagues. They all looked at me as if they had the same picture of dementia in their minds and shared a common view which was so clear that it should be immediately obvious to anyone. Disagreements later in the group show that this was far from being the case! (RN)

The early moments of the first focus group were stressful for me as a novice researcher. Helen delivered her response with such conviction that I momentarily worried that I had developed research questions to which everyone else had clear and straight forward answers! It took some minutes of further probing and tentatively reflecting on the limitations of their initial view, to engage the nurses in further exploration of the topic. The group continued and, ultimately, generated interesting data. However, the early minutes showed how the dynamic was altered by the tacit power struggle between a nervous novice researcher and nurses wanting to portray their knowledge of care within their own field. This power struggle demonstrated some of the power dynamics of the field and how these can be manipulated. For example, the nurses wore uniforms which identified them as nurses and were an indication of status, whereas I looked like a lay person. Furthermore, the nurses arrived together as a group and intimated that they could only stay for a specific length of time. This had, in fact, been pre-arranged with their Charge Nurse but they

reported this time parameter to me on arrival, marking out the boundaries of their participation. The nurses were keen to show their knowledge and appear expert and it was some way into the group before they seemed to accept my own understanding and interest and, along with this, the potential of the group to promote interesting discussion.

Confusion was often offered as an ‘initial thought’ rather than a fully considered response and, as such, it seemed to bring together ideas which were at the forefront of the nurses’ minds. While in the first extract the definition was delivered with unquestionable authority, over the course of discussion ‘confusion’ emerged as a pivotal concept but one which was understood differently by different nurses. For example, Leanne linked confusion to deficiencies in functioning.

SJR: So I’ve started all the interviews just very generally with asking what you think about when I say the word dementia. What does dementia mean to you? It could be at a personal level or in your work, whichever.

Leanne: Em, just no being able to say function at a normal level, but then what do you class as normal ay? Confusion, em, yeah I would say no being able to, to function normally. Definitely. (RN)

Her tone suggested that the presence of confusion should be assumed, as if this should be an obvious cause of the functioning difficulties. Victoria also considered confusion to be part of her initial thoughts about dementia and suggested that it incorporated disorientation and disinhibition.

SJR: Ok. Well I’ve started the interviews the same sort of way with everybody, just asking very generally what comes into your head when I say the word dementia? What does it make you think of?

Victoria: Em, confusion, em, sometimes the time and place. Em, people swear. I don't know what to say. (laughs). Confusion, yeh.
(RN)

For these nurses, dementia immediately made them think of confusion. It was seen as a dominant feature of dementia. They used the term to explain the presence of other features of dementia; for example, disorientation or problems with day to day functioning. Furthermore, they seemed to suggest with their tone that confusion and dementia are so inextricably linked that the connection is assumed and should be obvious to other nurses.

Moving away from the views that the nurses expressed as part of their initial thoughts, the nurses offered very considered responses about the links between dementia and confusion. These views focussed on differences and similarities between dementia and confusion and left behind the vision of confusion simply as one feature of dementing illness.

7.2.2 Contrasting Labels

Confusion is often a significant contributing factor in the admission of a patient to hospital and is, therefore, a significant feature of the patient's presentation. Patients may struggle with self care tasks and are more likely to fall while acutely confused. As a result, they are more likely to be admitted to hospital. Nurses working in acute areas talked about confusion and dementia interchangeably at times. While this may indicate difficulties in differentiating between these two diagnoses, it can be challenging to ascertain differences between acute and chronic confusion during the early part of an admission. Infection, electrolyte imbalance or vitamin deficiency are all common causes of acute confusion in the older person. A thorough screening process and treatment, where appropriate, can produce significant improvements in some individuals. With the acute confusion cleared, it is then possible to assess any

residual chronic confusion and consider dementia. However, in the early days of an admission it can be difficult to differentiate between acute and chronic confusion. Against the backdrop of these overlaps in presentation, it is not surprising that the nurses mixed their discussions of confusion and dementia. As outlined in the section above, many of the nurses recognised confusion as an important, perhaps defining, feature of dementia. Other contributing nurses conceptualised dementia by contrasting it with confusion. Most of them picked out differences between confusion and dementia, while a few considered the labels to be synonymous.

June talked about the presence of post-operative confusion in patients with and without dementia;

June: We have to keep a close eye on them if they're mobile. They've come in with usually a history of falls or something, it may be that they are not mobile. But, they might not realise they're not mobile. So we have to watch out for things like that. But that also happens with people who have no dementia but because of their surgery, have had an acute confusional state and it's the difference between the dementia and the acute confusional state that I think sometimes people get a bit muddled up with.

SJR: So what would you say are the, are the major differences?

June: Often with a person with an acute confusional state, they, they can understand simple, plain instruction. I mean sometimes people with dementia do that as well but sometimes the people with dementia it just, they don't have the comprehension to understand what you're saying to them. So obviously they have to be kept a closer eye on. We have had quite a lot of dementia patients who have recovered extremely well from fractured neck of femurs simply because, they have not been afraid to get up and walk on their feet. They haven't had the comprehension to understand that they've been through major surgery and what have you and they've actually recovered from their fractured neck of femurs extremely well.

SJR: Yeah I hadn't thought about that one.

June: I mean I'm not saying in every case. When patients are very mentally alert sometimes, and because they've maybe had previous

falls, they're very apprehensive about getting back on their feet again. We don't tend to get that with the dementia patients. They're usually very good about getting back up on their feet (RN).

June indicates that confusion is not exclusive to those with a diagnosis of dementia but may be evident in other post-operative patients too. She explains that there may be qualitative differences between acute confusion and dementia, particularly in terms of comprehension and following instructions. This assertion was not made by other nurses but is recognisable to me, from my own practice, where I could sometimes differentiate between acute confusion and dementia because of the way confusion presented itself. June also makes remarks about ways in which confusion relates to her care, considering it to be an indicator for extra nursing vigilance, particularly in relation to mobility. These remarks, along with her interesting comments about dementia having a fringe benefit in terms of rehabilitation, will be discussed later in the chapter.

June recognised differences between confusion and dementia. However, other nurses reported that they considered them to be synonymous. Emily reported that she could use these two terms synonymously;

Emily: At the beginning you know, they put down it's confusion.... You try and treat it with tablets like a UTI and it doesn't clear so you say oh. What point do you say it's dementia? How far do you go down the line to say the patient's got dementia? Like she's no gonna get a boil on her bum to say, oh there's dementia.

SJR: Well why is it important that we give them that label do you think? Do you think they need to have the label?

Emily: Nup. I just say. I don't actually. I just say confused. I feel it's the same and more understandable because they are confused. Because I mean, how can you label somebody with dementia? What's the ins and out of dementia anyway? Where if they're confused they're a bit ...forgetful. But there's other times you can have a

conversation with them. I mean, it might no have happened yesterday. It could happen 20 years ago but you can still get a good responsible conversation with them. And 9 times out of 10 with older people you always talk about what's happened in the past anyway. The war and everything. What it was like. How did you manage? You don't talk about oh what happened last week when you were at the shops.

SJR: So do you think confused and dementia are the same?

Emily: Yeah. I feel that and that's why I prefer, if it's gonna be a label it's gonna be confusion because I don't really know what they mean by dementia. To what extent is dementia? They've no got purple spots saying that's dementia you know. (RN)

In the extract above, Emily suggests that confusion and dementia are the same thing. While she intimates this clearly many other nurses used the words interchangeably during conversation, portraying similar ideas. Earlier in this chapter the differences between acute and chronic confusion were highlighted. This discussion in itself assumes an understanding of dementia in terms of enduring confusion and, while it does not rule out the possibility of other significant features, it places confusion in a dominant and defining position in explaining dementia. Emily's words highlight a number of issues. Firstly, she states that she considers dementia and confusion to be the same concept because, by her own admission, she lacks knowledge of what is specifically meant by the term dementia. She highlights confusion and forgetfulness as features which define her vision of dementia. However, she makes reference to the absence of visual clues or 'purple spots' which would be more tangible diagnostic features. Some of the challenges of diagnosis were raised in chapters two and five but the lack of knowledge of which Emily talks and the limited understanding that she displays, are important factors in this exploration of the conceptualisation of dementia. Lack of knowledge about specific disease labels and underlying neuropathology were outlined in chapter five and were factors which challenged the conceptualisation of dementia as a disease. Here again, lack of knowledge plays a part. Emily, a nurse with more than twenty years experience, is limited in her conceptualisation by her lack of theoretical knowledge of dementing illness. Issues

surrounding the educational preparation and continuing professional development of nurses will be discussed further in chapter nine.

Despite Emily's assertion that she does not favour the term dementia because of lack of clarity about its meaning, Emily does demonstrate an awareness of differences between acute confusion and dementia by using the example of urinary tract infection (UTI) in her interview. These remarks, along with her considerable clinical experience, raised questions about her firmly held belief that the term confusion should be used rather than dementia. Lack of knowledge, while significant, could not fully account for her single mindedness. Using Bourdieu's work as a framework for analysis required some examination of the power dynamics evident during the interview and some reflection on the interaction itself. Emily was keen to be seen as a leader within her workplace. Speaking in an authoritative tone, from a background of considerable experience, she enjoyed a position of significant power amongst the nurses in the field. She used emotive language to belittle the term dementia in favour of confusion and seemed enthusiastic in her assertion that her knowledge was lacking! At the time of the interview, Emily's data were difficult to explain. However, subsequent interviews and focus groups generated data which shed further light on Emily's views. A number of other nurses talked of their reluctance to use the term dementia. Indeed once this issue was recognised and reflected in the data collection questions, it became clear that this reluctance was more widespread than anticipated. Data generated around this issue will be presented in the pages which follow.

7.2.3 Stigma

The realisation that some nurses purposefully avoid use of the word 'dementia' was not immediately obvious during data collection. Poor diagnostic procedures, gaps in nurses' knowledge and limited awareness of specific diagnoses, initially, appeared to be adequate explanation for nurses using words such as 'dementia' and 'confusion'

imprecisely. However, over the course of early analysis, it became clear that other factors were also contributing to the language used by nurses. Some nurses actively avoided using the term ‘dementia’ and favoured ‘confusion’ in its place. This choice of language could always be justified with reference to imprecise diagnosis, non disclosure of diagnosis or the use of lay persons’ language, in order to enhance interaction with patient and family members. Flora gave an example of imprecise diagnosis;

Flora: I mean we had one woman she was a slight dementia. I don’t think it was really confirmed. It was like one of those dementias, a question mark sticks to it you know, with their profile when they come in. Em, and when she got on her feet she started to climb the stairs up to the fire escape. She could climb the stairs but she couldnae come back doon them again. Confused like, I would say right confused. (RN)

‘Confused’ became the word of choice in this example because the diagnosis of dementia was questionable, perhaps, because it had not been part of the admission medical history or, perhaps, formal diagnosis had never taken place. There are many possible explanations for imprecise diagnoses of dementia, some of which were discussed in chapter five. The result, in this example is that the nurse opts for the lay persons’ terminology, using the word ‘confusion’ to avoid an unconfirmed diagnostic label. By avoiding the label, the nurse also avoids the implications of that diagnosis, both medical and social. There is then no basis for discussion of prognosis or of the limited treatment options as outlined in chapter five. Similarly, there are no grounds for discussing social implications such as personality changes, disregard for social conventions or views of dementia which the social world holds. This important factor will be discussed more fully in the pages which follow. Flora also shows her avoidance of responsibility for the diagnostic label in the following extract;

SJR: If they come in with 'dementia question mark' on their form, then what would you then do? Would you do follow up with tests and things?

Flora: Well to be honest, it's, I'll just speak to the doctor that's in the ward at the time, whatever doctor we have. ... so if I've got a sort of question about it or if I'm no sure em... Best of all to speak to is the family you know... the doctor can. (RN)

The social world expects responsibility for diagnosis to fall to the medical or psychiatric practitioner, rather than the nurse, a point discussed in more detail in chapter five. Flora's actions are, therefore, in line with societal expectations. However, it might be anticipated that omitting to use the label may have implications for patient care.

Reflecting on my own nursing practice with older people, I can think of many examples where diagnostic labels were not discussed until formal diagnosis had been made or medical staff had spoken to the patient and family members. Information was not withheld in the face of direct questions, but protocol was respected and social expectations were met in that diagnoses were usually made by medical staff rather than nursing colleagues. However, in contrast to the observations in this study, the nurses in my own experience were sometimes aware of the implications of the diagnostic label, even while it was not in use. For example, while investigations were ongoing into an unexplained mass, nurses were aware of the potential for malignancy and planned care with that in mind. Specific treatments only began after diagnosis but, in the time prior to the labelling of the disease, nurses tacitly started to nurse that patient with the potential diagnosis at the forefront of their minds. This reflection on my own nursing practice carries minimal authority, as it is little more than an analysed memory of my own working life. However, it is enough to allow me to question why nurses who recognise features of dementia in their patients, choose not to consider dementia as a potential diagnosis. By choosing to use the word 'confusion' in preference, the nurses limit the potential of their care, as they are unable to address other symptoms which are present or consider prognosis or

advancing disease. In view of this reflection, factors which motivate the nurses' avoidance of the label were explored further and the data are presented below.

The nurses' gave a number of reasons for using the word 'confusion' in preference to dementia. Firstly, the word was used when formal diagnosis had not been made or was imprecise, as outlined earlier in this chapter. The language was also used in conversation with patients and their families. One reason for this is the variable disclosure of diagnosis of dementia, where some individuals are never told their diagnosis. This is a significant issue which is recognised within the field and discussed in the literature. Research has shown that the majority of both patients and carers would prefer to be given a diagnosis (Byszewski et al. 2007; Georges et al. 2008; Pinner & Bouman 2002; Pinner & Bouman 2003). However, Karnieli-Miller (2007) reports on the medical and psychiatric consultants' own difficulties and personal dilemmas in disclosing a diagnosis of dementia. Their discomfort with making candid disclosures contrasts with their legal and moral obligations, making disclosure of dementia an acutely uncomfortable process, both personally and professionally (Karnieli-Miller et al. 2007). Other individuals are told the diagnosis but can not retain the information, causing significant omissions when medical history is given at a later date. Molly highlighted this point when she discussed the disclosure of diagnosis;

Molly: When a patient comes in, we've got his notes there and if there's a diagnosis of dementia there, I never speak to the relatives about it because I'm never sure whether they've actually been told about it. Because we had a wee chap who lived with his daughter and he came in with increased confusion and I looked at his daughter thinking he's got dementia. So I said that. And she said but he hasn't got dementia. Nobody's ever told me he's got dementia. He's got confusion. So I thought well, as a staff nurse on the ward it's no really my place to argue with her and say but he has got dementia cause it's diagnosed here. I said, well it's actually got an awful lot better since we cleared up his infection and you know his confusion's a lot better. But somebody, at one point had diagnosed dementia but hadn't discussed it with her. Whether they'd discussed it with the patient or

not I don't know, but the patient didn't tell us but the daughter certainly couldn't. (RN)

Molly used the word 'confusion' in order to avoid a future confrontation over an unconfirmed or undisclosed dementia. Her remarks also highlighted how her understanding of the role of the nurse influenced her language and her approach. She did not feel that her position within the field and the power dynamics within her workplace allowed her to disclose the diagnosis to the patient's daughter. Rather than upset the dynamics of the field or overstep the perceived boundaries of her authority, Molly moved the conversation away from the discussion of the label. In doing this Molly diminished her own position, allowing the patient's daughter to assume that she had mistakenly used the label. However, she also avoided a potentially challenging conversation about dementia, by refocusing the conversation on the word confusion.

The role of the nurse has clearly been influential in determining how Molly chooses to discuss dementia and confusion with people in her care. The challenging nature of a frank discussion about dementia may also serve to dissuade nurses from discussing dementia explicitly and may lead to the use of the word 'confusion' in place of 'dementia'. Molly went on to justify her use of language, suggesting that lay people understand the term 'confusion' more readily than 'dementia'. However, the following extract also reveals her personal feelings about the word 'dementia' and the image that she attaches to the term;

Molly: Well, confusion is something that I think relatives understand which helps.

SJR: Yeah? Perhaps it's easier to understand. But I wonder then if we don't understand that there might be swallowing problems and mobility problems and such a global impairment as there could be with dementia.

Molly: Yes. I see dementia as something that is much more than confusion. It's, just the word. It's a horrible word. Dementia is just.. I don't think it's a nice word. Doesnae conjures up nice thoughts. It conjures up sort of people who dribble and, you know, can't speak or who get their words muddled up or just can't do anything. They're just sort of sitting there. Just existing. (RN)

This stark admission from Molly about her own vision of dementia demonstrates that, while she may use the words interchangeably, Molly does not conceptualise dementia and confusion in the same way. She understands dementia to be more complex than confusion with more features and a potentially debilitating progression. Other nurses reiterated Molly's distaste for the word 'dementia' and the connotations which the word carries with it. The following extracts show nurses' perceptions of dementia as socially unacceptable;

Ava: It's just such an unacceptable illness. And it's such a horrible word, dementia, demented, Mmmm. It would be awful to tell someone they've got dementia. It's not like saying you've got ... oh I don't know, something wrong with a limb or something. (RN)

Angela: Sometimes you dinnae use the word dementia. You just say oh, you know, if you've forgotten what I told you yesterday or ... has this been a problem that you forget you know?

SJR: Yeah, so you'd probably talk about forgetfulness rather than dementia as a word?

Angela: I think I would yeah. I think I would. Even to some relatives as well because they dinnae want to admit sometimes. Because sometimes the relatives see it as an added burden to their already busy life.

SJR: So there's a bit of a stigma?

Angela: I think there is. I think there is. (RN)

These nurses openly admit that they use language to distance themselves and the people in their care from the negative connotations of the word dementia. Nurses, patients and family members all live within the social world and are subject to the influences within that world. These influences shape the society in which we live and provide the backdrop to interactions that the nurses have with the families in their care. Acceptability is socially determined, changing over time in response to influences such as increasing knowledge, public policy, social structures and organisation, the legal changes and the media. Stigma is a socially situated phenomenon. Goffman (1968), in his seminal text on stigma, considers three categories of stigma; abominations of the body, blemishes of individual character and tribal stigma of race, nationality, religion. He suggests that stigma, in the context of ill health, is most evident when an individual lives with an incurable or progressive condition, has symptoms which can not be concealed and when a disease process is poorly understood or feared by the general public (Goffman 1968). Goffman's indicators for stigma could all be true of dementia. The nurses also raised other factors which are significant within the social world in which we live. These are discussed in the following section.

Some of the nurses suggested that the stigma attached to dementia was related to the stigma associated with mental health problems generally (Freidl et al. 2008; Peris et al. 2008; Spagnolo et al. 2008). By virtue of its organic brain pathology, dementia is not always grouped with other mental illnesses and is commonly related to ageing. This too may be a source of stigma, as western society commonly views ageing negatively. Furthermore, society values cognitive function highly. Competence and decision making capability are highly regarded and are the subject of much discussion in health care and legal circles. In society at large, high levels of cognitive function are required to complete even the simplest of everyday tasks. For example, in order to collect a pension, an older person must remember a unique pin number and be able to key it into a terminal in order to access funds. Individuals value their decision making capability and independence. Any deficits which challenge these capabilities also challenge the individual's membership of society and have the

potential to stigmatize that individual. Lauren notes that dementia may be deemed unacceptable because people fear it;

Lauren: you can explain to them in every possible way that you can think of what the situation is. That they're not going to get better, that you know given time they will deteriorate and they don't want to take it in. And who knows, I might be the same myself if I, you know, got told, gosh.

SJR: Yeah it's difficult to put yourself in that position isn't it? You can't think of it.

Lauren: I mean this person had been married to you for 40 years you know I mean. So I think it would be easier for me if cancer where there's a start a middle and a finish and it's got a sort of a set time.

SJR: People seem to understand cancer better don't they?

Lauren: And it's socially acceptable. It's acceptable.

SJR: And why do you think dementia's not acceptable?

Lauren: It's too frightening.

SJR: Yeah?

Lauren: Too frightening. Maybe it'll become more acceptable as, as people are living longer and there's more people, not just living longer, people just seem to be developing dementia. (MH)

Lauren suggests that the unpredictability of dementia could lead individuals to fear it. Furthermore, there is fear attached to losing independence or decision making capabilities and fear associated with behaving in socially unacceptable ways. During data collection a number of nurses indicated this with remarks such as 'she would hate it if she could hear herself shouting like this'. Seeing patients who are no longer able to behave in socially acceptable ways leaves the nurses fearing these aspects of dementia.

The data presented in this chapter have moved from the nurses' initial thoughts about confusion as a feature of dementia, to contrasting confusion and dementia as diagnostic labels. The challenges of distinguishing between acute confusion and dementia were outlined. Data surrounding the use of language were presented, showing how some nurses consider the terms 'confusion' and 'dementia' to be synonymous, while others favour the word 'confusion'. Problems associated with the disclosure of a dementia diagnosis and attempts to make the terminology more accessible to lay people were given as examples of reasons to favour the use of the term 'confusion'. However, stigma was the most influential factor in determining language use, as nurses shied away from use of the word 'dementia' in order to distance themselves from distasteful images which they associate with dementing illness. This chapter now moves on to consider a significant difference between confusion and dementia, focussing on some of the challenges that this raises for patient care. The frequently used term 'pleasantly confused' will then be explored before practical challenges associated with conceptualising dementia in terms of confusion are discussed.

7.3 Confusion and Dementia – ‘Entirely Different Things’?

Much of what has gone before focuses on similarities between confusion and dementia. However, Moira highlighted one significant difference which has important implications for patient care. She considered the distinction between confusion and dementia to be encapsulated in the phrase 'no going back'. The following extract shows how she differentiated between the two terms and how this comparative account stresses the potentially devastating extent of dementia.

SJR: I wanted just to check out with you about the difference between confusion and dementia. Some of the nurses have suggested that confusion and dementia are the same.

Moira: No they're not. That's my opinion. They're not. No no. Confusion, you can have confusion for a myriad of things. Em, if you

have an infection for instance you could be confused. It's a different type of thing from dementia. It may portray itself similarly. You could be confused through lots of things like stress and all sorts. I think the confusion from dementia is a different type of confusion. It's a frightening experience for them. It's, it's a totally different ball game I think, altogether from, from somebody who is just confused. When it's a dementia you're having, the confusion becomes worse. There is no going back from it and there is no coming out of it. A few periods of insight maybe along the way.

SJR: But there's no going back.

Moir: There's no going back anywhere. They're not going back to being you know, able to make rational decisions any more and where confusion it's. It's a big word that to label on anybody as well, confusion. Em, but dementia I think is an entirely different thing. That's my opinion of it anyway. (MH)

This extract is significant in that it highlights the irreversible nature of dementia and stresses this with the phrase 'no going back'. Moira refutes any similarity between confusion and dementia considering that the scope and irreversibility of dementia set it apart from confusion. This proved to be a rather polarised view, as the majority of contributing nurses could see some areas of overlap between confusion and dementia. However, Moira's views did highlight a significant issue in terms of patient care. Those nurses who considered confusion and dementia to be synonymous, limited their view of dementia significantly and did not take any account of Moira's ideas about there being 'no going back'. That is to say, the nurse who understood dementia to mean simply being confused could not incorporate ideas about irreversibility or the potential scope of the disability in their care of the patient.

Emily suggested that both terms could be used interchangeably and she did accept that this view precluded a link between confusion and some of the other features of dementing illness, such as swallowing difficulties or incontinence;

SJR: Do you think if you say confusion, nurses would understand that patients might have swallowing problems and mobility problems and speech problems all as a result of that confusion, as they could have with dementia?

Emily: Mmmm. I never thought of that one. I mean when I say confusion I mean they're a bit forgetful and that but, then if they've got any small problems I mean we individualise that saying. the person's got a bit of a swallow problem. You know, I didnae class all that, any of that, with the confusion side of it. Confusion's the forgetfulness.

SJR So you probably wouldn't link swallow problems with dementia really?

Emily: No. But I mean, on saying that, they do forget to swallow.
(RN)

This extract highlights the significant limitation of understanding dementia exclusively in terms of confusion and considering the two terms to be synonymous. This conundrum takes the reader back to the impetus for this study and my experiences caring for Sally and her family, outlined in chapter one. The experience of caring for Sally made me question how nurses conceptualise dementia in the light of some nursing colleagues celebrating a diagnosis of dementia. The contrast between a colleague's understanding of dementia as an inconvenience involving forgotten shopping lists and misplaced keys and Moira's view of an irreversible condition from which there is 'no going back', seems stark.

Conceptualising dementia in terms of confusion may have both benefits and limitations for nurses. Through the process of comparing and contrasting confusion and dementia, nurses may arrive at some of the most significant similarities and differences between these two diagnostic labels. However, the data suggest that lack of knowledge may hamper this process, limiting the nurses' insights. To suggest that confusion is one feature of dementia among many others may have the most utility in terms of patient care. There is huge significance in the nurses' use of language in this area. Nurses may choose to use the term 'confusion' rather than assign the socially

less acceptable label of ‘dementia’. This subtly changes the way that confusion and dementia are regarded, both by nurses and members of the public within the field. This manipulation of language is likely to be motivated by the nurses’ desire to distance themselves from the negative images of dementia, protecting both themselves and those in their care. This theme will be explored further in the following section which considers data about the frequently used phrase ‘pleasantly confused’.

7.4 ‘Pleasantly Confused’

Throughout the data collection process contributing nurses talked about patients being ‘pleasantly confused’. I understood this terminology from my own practice and did not initially question its meaning. However, it became clear that this terminology was not readily understood by all nurses and its meaning, therefore, had to be considered in more detail. Despite the large body of data concerning this topic, those nurses who recognised the terminology were in almost total agreement about their definition of the idea. A second group of nurses could not identify with the phrase in any way. There was a clear split in terms of workplace, with nurses in medical inpatient areas understanding the phrase while those from mental health areas did not recognise the phrase at all. While this split also largely represents the division of nurses by education, this is not entirely accurate, as a number of the mental health nurses had previously been educated and registered as general nurses.

There is a surprising level of agreement between respondents on the topic of pleasant confusion and the data split clearly into three areas. Firstly, ‘pleasantly confused’ was used by nurses as a phrase to explain or demonstrate an individual patient’s personal response to the effects of dementia. It was not used to describe their emotional response to diagnosis or their feelings about their decline but, rather, as an unspoken demonstration of their response during the time when reasoned analysis of the predicament is no longer possible. For example, Helen suggests that the patient

she describes in the extract below has accepted her dementia and demonstrates her acceptance through humour and calmness;

Helen: She laughed when she said 'I'll come back but I'll not know who you are'. I suppose that's the really strange thing, isn't it? So how much do they really know then? Cause they all cope with it in various different ways and that was obviously her way of coping, you know. She'd say things like, 'have I had a cup of tea already this morning or not?' (sniggers)

SJR: Yeh

Penny: We used to have some good discussions. After a while she went off but...

SJR: So would you say that she'd come to terms with her dementia then?

Helen: See that's something that you would say that she's pleasantly confused. Cause she, there was that kind of daft humour, so maybe she had come to terms and had accepted it (RN).

In this excerpt, the phrase 'pleasantly confused' encapsulates for Helen the relaxed and undistressed way in which this individual has reacted to her dementia. In this example the patient has some insight into her memory deficiencies, as her joke in the first line exemplifies. However, this is not necessarily typical of the patients described as 'pleasantly confused'. In the main, use of the term 'pleasantly confused' assumes that the person labelled is not in the early stages of dementia with symptoms of mild confusion but, rather, experiences considerable impairment. This was never stated specifically by the nurses but most of the individuals described were considered to lack insight into their current state of confusion, have limited perception of their own deficiencies or difficulties and to suffer no noticeable distress. The lack of upset or torment means that those labelled 'pleasantly confused' enjoyed a happier disposition than many of their counterparts and this seemed to be a key feature of the label.

Angela used the phrase ‘pleasantly confused’ to describe a patient’s reaction to the diagnosis and decline of dementia. She also raises the important issue of compliance.

SJR: I’ve heard nurses talking about people being pleasantly confused. Can you tell me what that means?

Angela: Well that, I think that, I think that means it’s the people that like I said that are, don’t really understand what’s going on and they’ve just drifted into dementia and never fought against it. So, you see, they’re compliant as well. I would see, people as pleasantly confused as compliant and that’s wrong like, I think. Em,

SJR: But that’s definitely part of that. I can recognise that

Angela: They seem to be quite happy in the state that they’re in.

SJR: But you say they’ve maybe drifted along, drifted into that.

Angela: So, they really dinnae want to change anything and they come into hospital and they’re maybe, appear confused but you get the ones that dinnae try to get up on their own. They just seem to be quite happy with their situation. Does that make sense?

SJR: I think it makes sense.

Angela: But I see them as more compliant. They’re quite happy to get washed and dressed and you do everything for them. They’ll eat their tea, they clear their plate. You’ll say, Oh you’ve done well you know.

SJR: Yeah. They’re nice patients to look after. I can understand that.

Angela: But they just dinnae fight against it. Whereas the ones that are not pleasantly confused, they’ll argue black’s white even though they’re wrong! (RN)

Angela contrasts the individuals who fight against the diagnosis and those who do not display any aggression or fight in their reaction. Pleasant confusion, therefore, seems to incorporate some passivity which allows individuals to react calmly, despite the erosion of autonomy which is inherent in dementia. The image of a passive patient ties in with many of the other things nurses said about pleasantly confused

patients and the way that they react, both to their dementia and the nurses caring for them. For example;

Pete: I would say that if somebody's pleasantly confused they're just not agitated. ... the pleasantly confused patient for me, from how I see it, is somebody who is not agitated with themselves. (RN)

Molly: Well, I think pleasantly confused means that they're not aggressive. They're smiley, happy, but they can't tell you their name. that's pleasantly confused. (RN)

These comments highlight the passivity associated with so called 'pleasant confusion' and incorporate the view of pleasant confusion as an individual reaction to dementia and its effects.

The second use of the phrase 'pleasantly confused' related to the nurses' responses to this group of patients, rather than the patients' own reactions. Pleasantly confused patients were considered to be 'good patients'. They caused the nurses very little trouble during their daily routine and did not demonstrate behaviours considered challenging. Compliance with the ward routine, social norms and nurses' expectations all contributed to this 'good' behaviour. This made the work of the nurse easier during the course of a shift and led to the nurses feeling more positive about this group of patients, than those who posed more challenges. Many of the nurses expressed these ideas, giving examples of patients being 'well behaved' and, therefore, making the work easier. For example,

SJR: Some of the nurses have talked about patients being pleasantly confused. What would you say that means?

Marjorie: I would say that means somebody who was non aggressive and was compliant.

SJR: Yeah ok.

Marjorie: And he smiles and sings and. (laughs)

SJR: So nice patients to look after?

Marjorie: Likeable aye, yeah. (RN)

SJR: Some of the nurses that I've spoken to have talked about people being pleasantly confused. I'm intrigued to know what pleasantly confused is. Can you tell me what you think it is? What does that mean?

Fiona: As opposed to the violently confused. (laugh) ... They're always nice to you.

SJR: They're nice to you as nurses?

Fiona: Yeah and they're always polite and nice and they go along with you.

SJR: Ok.

Fiona: Completely away with it but quite content. They're usually the singers. (RN)

Both of the above examples suggest that the patients being described are compliant. They do not challenge the nurses and are enjoyable patients to look after. Lack of aggression and challenging behaviour is part of the image of the 'good' patient but lack of personal distress is also key to the label of pleasant confusion.

The lack of distress experienced by the patients made the interaction between nurse and patient much easier than with those patients who suffer torment and distress. Leanne highlights this issue;

Leanne: We have patients in the ward and they can have the diagnosis of having dementia but they can be pleasantly confused. I find it really horrible, when they're not so pleasantly confused and they're anxious and like continually agitated and it's like they're tormented and it's, it's hard. Well it's hard for me personally to, to look after. I find it quite difficult. (RN)

The label 'pleasantly confused' allowed the nurses to put distance between the undistressed, cooperative patient and the unpleasant diagnosis of dementia. The phrase was used by the nurses as a defence against the huge social significance and personal horror of dementia. By describing individuals as 'pleasantly confused' the nurses could choose to ignore the potential significance of dementia, with its unpleasant effects and enjoy interaction with the patients without any of the fear or negativity associated with dementia. The nurses were, therefore, happy to consider patients to be 'pleasantly confused'.

The nurses' response to the group of patients they describe as pleasantly confused says much about their own, perhaps unspoken, thoughts about dementia. The label 'pleasantly confused' seems to be used to put distance between those who demonstrate the unpleasant or challenging effects of dementia and other individuals who do not. Using the phrase allows nurses to see the patient who is confused but undistressed and who behaves in a pleasing manner, as different from a patient who demonstrates other effects of dementia. The individual's behaviour need not fit social norms; for example, a patient may sing or giggle in a manner which does not fit strict social codes. The behaviour is, however, pleasing to the nurse. This hints at the nurse's reluctance to think about the negative effects of dementia and the corresponding desire to concentrate on the less distressing effects, giving them a new and positive label. It also makes clear that nurses find the distress and torment often associated with dementia to be personally distressing. Thereafter, the label of 'pleasant confusion' actively excludes this distress while describing a positive feature of the patient's confusion also serves to make the confusion more acceptable for the nurse. Finally, the nurses' comments highlight the challenges associated with

working with those who have dementia and the nurses' drive to alleviate some of these difficulties by reconsidering the diagnostic labels and assigning new, more positive labels.

This process of using language to distance the nurse from the negative images of dementia could be described as a defence mechanism. In groundbreaking work during the early nineteen sixties, Isabel Menzies examined ways in which nurses exhibited anxiety in the workplace and the effects that this anxiety had on effectiveness (Menzies 1961). Following her study of nurses in general hospitals she found that the social system at work within a hospital was flawed. She concluded that;

“the social defence system represented the institutionalization of very primitive psychic defence mechanisms, a main characteristic of which is that they facilitate the evasion of anxiety, but contribute little to its true modification and reduction (p25).”

This fundamental flaw, she argued, resulted in ineffectiveness, high staff turnover and poor practice. While nursing practice and structural aspects of the hospital have undergone major change since 1961, it could be argued that ‘pleasant confusion’ is an example of the phenomenon that Isabel Menzies sought to highlight. Through the social systems of the inpatient setting, nurses have developed a strategy of language use which allows them to avoid some of the anxiety attached to dementia and their work with dementia patients. In this case, nursing anxiety is reduced by seeing undistressed patients and being challenged less frequently in their nursing role by the largely compliant, pleasantly confused individuals. Despite being nearly half a century old, the work of Isabel Menzies appears very pertinent to the field of this study.

A final group of nurses did not recognise the idea of ‘pleasantly confused’ from their practice. These nurses worked in mental health areas. They were all qualified as mental health nurses, although some of them had, previously, trained and worked in general medical areas. The phrase was not something that they understood from previous experience nursing in medicine. Indeed, the concept of ‘pleasant confusion’ was completely alien to this group of nurses. The workplace is clearly an influential factor in this rather anomalous situation. Mental health settings differ from the general medical areas quite considerably in terms of the patients who pass through the services. For example, nurses in the general medical areas meet people who live at home with dementia and those admitted from other residential settings who have specific medical problems. Those who come into hospital from home are, typically, less severely dementing than those from the long term care settings. As a result, nurses in the medical areas usually care for people with less severe dementia than their mental health colleagues. Furthermore, individuals who demonstrate challenging behaviour are commonly referred to mental health services, even if these behaviours are a feature of early stage dementia. The mental health nurses could, therefore, be said to have contact with both the more severely dementing and those with more challenging presentations. This may, in part, account for the non recognition of ‘pleasant confusion’, as the majority of patients seen by mental health nurses are either more severely dementing or are distressed and agitated by their condition. Lauren explains this;

SJR: A number of nurses have talked about patients being pleasantly confused. Is that something that you would talk about or is that a foreign language?

Lauren: No. Well, the patients that come here are here because they cannot be, looked after in any other area. Their behaviour is at such a level that they have to ... well (shrugs)

SJR: So pleasantly confused doesn’t really come into it.

Lauren: Doesn’t tally (laughs). Having said that, once they’ve been in for a time they might then go on to become pleasantly confused. But when they come to us, their behaviour is such that it’s the aggression or the agitation. They’ve got beyond that. They’ve got the worse kind

of, end of dementia. I mean there are some I'm sure that are pleasantly confused but our patients here I would say have got the worst kind of dementia. Some of them are very angry. (MH)

Lauren mentions that the patients in her care may have 'gone beyond' pleasant confusion which suggests that, although it is not terminology which she uses or recognises in her own practice, she is aware that it may be a feature of either an earlier part of the dementing process or of some individuals' experiences.

Some mental health nurses could not fully grasp the idea of 'pleasant confusion' despite having an awareness that others use the terminology. Maria stresses that none of the patients should be considered 'unpleasant', which would naturally follow from the nurse considering certain patients to be 'pleasant'. The unpleasant features of the dementing process she relates to the disease process and not to the individual.

SJR: Nurses have mentioned this kind of terminology about being pleasantly confused.

Maria: Well I suppose maybe they're just talking about maybe patients that are still quite independent physically, and mentally as well but, can become confused at times. Maybe that's what they mean you know.

SJR: It's quite interesting just to, to see the different terminology.

Maria: I mean I wouldn't look at anybody in here and say there was anything unpleasant about you know,

SJR: No. That's true.

Maria: I mean, even the aggression side I can completely understand that that's part of the dementia disease. You're gonna get that with em, you know with the sort of ongoing process. I mean it's an illness. It's their illness. I wouldn't ever think oh so and so's aggressive and you know, that's not very nice or whatever.

SJR: Yes. You're not blaming them. It's not their fault.

Maria: No not at all cause you can't, you just can't. (MH)

Maira recognises the phrase but finds it difficult to understand;

Maira: No, no. I, I don't really like that. How could you be pleasantly confused if you think about it and break it all down? You know, you're confused yes but are they meaning that they're not aggressive? Is that what they're meaning? That must be what they're meaning. They're not aggressive and they're easy to deal with for them.

SJR: Yeah I think they're compliant.

Maira: I think the care must be easier for them. Yes. I think that's what it must be.

SJR: They're patients who don't cause them any trouble is the impression I've got.

Maira: Yes. Well that's exactly what it is. It's not a nice expression. No I don't like it. (MH)

In summary, the data on 'pleasantly confused' which have been presented in this section, displayed an overwhelming common understanding of the phrase among nurses working in general medical areas. Those from mental health care settings were equally clear in their rejection of the phrase, although a number of those nurses were able to interpret the meaning of the phrase with some accuracy. By virtue of the nature of 'pleasant confusion', this group of patients could be said to be easier for nurses to care for. These patient showed no outward signs of distress or anguish and, while their behaviour may not always fit social norms, it is generally pleasing. Furthermore, these patients complied with nurses' earning themselves the label of 'good patients'. By labelling this group of patients 'pleasantly confused', the nurses distanced themselves from the unpleasant aspects of dementia and used the label as a defence against the anxiety induced by dementia and its wide ranging implications. The work of Isabel Menzies (1961) provided a useful frame of reference for this

discussion, as her study explored anxiety and its effects on the social systems within a general hospital during the 1960s.

7.5 Confusion and Care

The final section of this chapter will consider how conceptualising dementia in terms of confusion can have an impact on care and care planning within the study field. Unlike disease and memory as ways of conceptualising dementia, many of those who focus their understanding around confusion have developed this understanding through the care of individuals. In an inpatient setting, confusion can be exacerbated by anxiety, unfamiliar surroundings, infections and bed moves, among other issues. Nurses are often faced with practical problems in the ward area which are the result of patient confusion. For example, patients may be found climbing into the wrong bed or failing to find the toilet. As a result, confusion is often the focus of the nurse's care and the most obvious feature of dementing illness. The dominance of confusion as a feature in the clinical area, in turn, shapes the nurses' conceptualisation of dementia more generally. Against this backdrop, it is not surprising that many of the nurses talked about confusion in relation to their clinical work. Most of the data focussed on environmental issues, which raised a number of difficulties for patients with dementia.

The ward environment is a challenge for those who have dementia. The move from a familiar home environment is, in itself, unsettling. Hospital wards are often difficult to navigate, with long connecting corridors and numerous doors which can cause disorientation and many bed space areas looking similar. This disorientation is heightened when the patient has dementia. The example below shows ways in which many of the nurses sought to alleviate confusion, caused by the ward environment;

SJR: If you hear that someone is coming to your ward with dementia what do you immediately think of? What kind of approach to care might you take?

Andrea: They're obviously confused so I think you try to keep things as simplistic as possible, you know. You have their bed, you make sure their name's above their bed, you know, there's a sign for the toilet. You just orientate them, well usually start just within their room until they start wandering! (laugh) .. and think that they're in the same bed in the next bay!

Margaret: Oh yeh. (shaking head, smiling)

Andrea: Anyway, you try and just have signs so that they know, and you know, there are maybe pictures at the side of their bed and, so that you can say to them, you know that's your name and this is your bed and... Try not to move them about too much, try and keep them at the same bed. I know we've moved a few of them and they don't know where they are. The minute you move their bed, they're lost. (RN)

The environmental difficulties which challenged dementia patients also caused the nurses distress and anxiety. Many nurses from a variety of clinical areas talked about the inadequacy of their ward environments. These discussions centred on two main related points. Firstly, the layout, size, acuity and décor of the ward spaces were thought by nurses to be unsuitable for the care of people with dementia. Each ward included in the study looked different but none had been purpose built for the care of those with dementia. Some wards had gone to great length to improve the environment, making it more suitable for the patients in their care. This included painting of wall murals, placing of furniture, creation of quiet spaces and the inclusion of sensory stimulation areas. In some longer stay areas these amendments to the ward were both possible and beneficial. Patients in these settings also had many personal items around their bed areas and had photographs on their room doors to act as a visual prompt. The acute areas, however, were not able to change the environment as radically, with strict infection control guidelines and more medical equipment restricting the attempts to personalise the ward areas. The ward environment was a great concern to many of the nurses and will be discussed further in chapter eight. The lack of light, restricted access to outside space and the long

corridors linking one ward to the next were particular environmental concerns of the nurses. Measures taken to improve the environment were mostly undertaken by nurses and often were completed in their own time, showing the commitment that many had to the improvement of the care environment and the importance that they placed on this aspect of their care. It also showed how distressed the nurses were by their immediate work environment.

Related to this first point about the inadequacy of the ward environment, are the nurses' feelings of ownership of their patients. The ward environment was closely related to this sense of ownership. While the majority of the contributing nurses felt that the ward environments did not best suit the needs of the patients, the nurses' responses to this environmental inadequacy split into two distinct groups. Some worked hard to improve the environment, as outlined above. This often involved a great deal of personal effort and time which was not part of their nursing role. The second group, however, suggested that individuals with dementia should not be placed in their ward because of the inappropriate surroundings and the disruption that they caused to the life of the ward. As might be expected, these nurses, typically came from more acute areas where dementia care was only part of their caring role. Nurses working in mental health admissions units, rehabilitation, orthopaedics and acute medical areas all stated during data collection that individuals with dementia should not be placed in their areas. When asked for more details about their claims, the nurses all cited difficulties in giving good quality care because of the constraints of time, environment or acuity within the ward. These claims were not false and represented the stretched system within which the nurses work. Juggling the varying demands of a confused patient, alongside an acutely unwell individual, was a challenge which was observed during data collection. These very real demands caused great anxiety within the ward. The over-riding stress and anxiety which resulted were clearly transmitted to patients, further diminishing the quality of the environment for dementia care.

While discussing the day to day care carried out on the ward, the nurses repeatedly used the word confusion and linked it to dementia. Confusion was used synonymously with dementia at times while, at other times, nurses described confusion as a key feature of dementia. In discussion of care, the detail of the conceptual relationship between confusion and dementia was secondary to the fact that it was the confusion which they faced in their day to day work. The conceptual links between confusion and dementia were largely lost when dealing with a confused patient on a busy ward. This point underlines the importance of ensuring that understandings, gained through studies such as this, are used to inform practice in the future.

7.6 Conclusion

This chapter has focussed on the conceptualisation of dementia in terms of confusion. Confusion was a dominant theme in the data and one which was the focus of a great deal of the practical nursing care. Data have been presented to show the variety of ways in which nurses linked confusion and dementia. While some nurses considered confusion to be one among many features of dementia, others believed that the two words could be used interchangeably. This limited their view of dementia to be simply a chronic confusion. The nurses came upon a number of challenges in differentiating between dementia and confusion. These related to difficulties in identifying acute confusion, poor knowledge of dementia and limited diagnostic information.

Significantly, the nurses showed great reluctance to label people with dementia. Data were presented which showed the nurses avoiding the use of the word 'dementia' in favour of the term 'confusion'. By manipulating language in this way the nurses avoided thinking about prognosis or about some of the other features of dementing illness. These strategies allowed the nurses to distance themselves from the negative effects of dementia and focus on the more manageable effects of confusion. While

this may protect nurses it is also likely to limit patient care by preventing the nurses looking to the future or integrating the care of various dementia symptoms. The stigma surrounding the word 'dementia' was found to extend to other areas of society, reflecting the feelings about mental frailty, old age and diminished capacity.

The chapter then moved on to consider those nurses who found the terms 'dementia' and 'confusion' to be entirely different. The phrase 'no going back' was significant in highlighting the key difference that nurses recognised between dementia and confusion. The irreversible nature of dementia and the life changing nature of the diagnosis struck a cord with me, personally, and reflected some of the original aims of this work. These factors were discussed and some of the limitations of conceptualising dementia in terms of confusion were outlined.

The often used phrase 'pleasantly confused' was explored in some detail and data were presented to show the overwhelming similarity of the nurses' definition of this phrase. Used by many nurses and understood by many more, the phrase became a device used by the nurses to distance themselves from the challenges of dementia. The work of Isabel Menzies (1961) was used to highlight the functioning of social systems and, in this case, the use of language as a defence against anxiety. Although not an effective strategy for removing anxiety, the use of the phrase 'pleasantly confused' and the picture which it conjured up for nurses, was a useful way for them to avoid anxiety in their workplace. There were a number of nurses who did not relate to the phrase and this was also highlighted.

Finally, this chapter considered how the conceptualisation of dementia in terms of confusion, may relate to care. Significantly, confusion was often the focus of care, at times, with little reference to dementia. Environmental concerns were dominant, with nurses discussing the challenges of ward geography and organisation, as well as décor and ambience. The disorientation resulting from a change in environment and the resulting practical difficulties were distressing for both staff and patients alike.

Staff responded in different ways to these challenges, with some committing time and energy to improving the ward environment. Others felt that dementia patients should not be admitted to those care areas and highlighted difficulties in giving quality care with the conflicting demands of acutely unwell and confused patients.

CHAPTER EIGHT

DEMENTIA – “ROAD TO NOWHERE?”

8.1 Introduction

This chapter introduces the metaphor of the journey as a way of conceptualising dementia. This frequently used metaphor was employed by nurses throughout the data collection process and sheds some light on their ideas about what dementia is and how these ideas relate to care and care planning. The chapter begins by defining ‘journey’ and discussing its use in the context of the study field. Thereafter, the chapter moves on to discuss ways in which nurses in this study apply the metaphor to dementia and how this can be contrasted with some traditional notions of ‘journey’. Data are presented to demonstrate the two emerging dementia journeys outlined by nurses. Following the outline of each journey, discussion highlights the significance of the journey for care practice and some reflective remarks are made. The chapter concludes by contrasting the nurses’ two different approaches to the journey metaphor and highlighting emerging challenges for practice.

8.2 Journey in Context

The metaphor of the journey has been used in a variety of ways in healthcare. It is, arguably, a somewhat overused metaphor and not one which I would have chosen to use in this work. However, perhaps because of this popularity within the field, the language of journey was used throughout the data collection phase of the study, as nurses sought to describe how they conceptualise dementia. Some of their contributions include some ideas which differ from traditional notions of journey and

this, along with the dominance of the theme emerging from the data, encouraged my presentation of 'journey' as a key means of conceptualising dementia. The nurses use some vocabulary which is directly related to ideas about 'journey' but the data also show ideas about movement and progression which have been analysed alongside the material, which relates more specifically to the journey theme. The ease with which the nurses use terminology related to ideas of journey shows how comfortable they are with this metaphor and how much part of the habitus of the field these ideas have become. Assumptions about the concept of journey are also made by nurses who simply talk about movement and progression, assuming an underlying understanding of the metaphor. Ideas about journey have, therefore, become commonplace in healthcare and have gained capital within the field through their use in policy documents and academic healthcare literature. In policy documents it is common to find the phrase 'patient's journey' relating to the movement of a patient through the healthcare system from initial contact with a service to eventual discharge. Policies aimed at making this journey more smooth and efficient are highlighted to nurses through verbal and written updates, bringing this metaphor to the forefront of nurses' thoughts at regular intervals throughout their practice careers. In one clinical setting the policies relating to laundering soiled or contaminated linen was prefaced with a flow chart showing the 'journey of a sheet' through the hospital laundry service! The metaphor of journey, therefore, pervades all aspects of policy within a hospital. This dominance and the authority underlying the delivery of the message contribute to the power of the metaphor within the field. Over time, this has developed into more general use by individual nurses as the language of authority starts to become integrated into the language of the ward nurses. The metaphor of the journey has become part of the habitus of the study field and is often used unthinkingly by individuals and with assumed meanings.

Further to the use of journey in policy, nurses also encounter the concept of journey in the wider social world and in academic literature. The sheer volume of references with the word 'journey' in the title or keywords is astounding. A search using only Medline and CINAHL produced over six thousand references and over eighty of

these had publication dates within a month of the search date. Reviewing some academic literature from a range of clinical areas has allowed an insight into the use of the journey metaphor in the wider research context. While the literature review was not exhaustive, it was clear that many papers made only passing reference to the journey metaphor in the text. It was common to find 'journey' as a keyword or in the title, perhaps demonstrating the usefulness of the metaphor in portraying ideas about progression or motion to a potential reader (Beebe 2006). The metaphor of the journey is readily understood and may appeal to readers who are attracted by the instant recognition and comforting familiarity of the idea. Miles and Huberman (1984) describe metaphors as useful devices which reduce data through the compiling of a range of ideas in one single and familiar metaphor. While the metaphor is familiar in common parlance, additional ideas may be included when it is used in a healthcare context. For example, some authors used journey synonymously with disease trajectory (Leydon et al. 2003; Lunney & O'Mara 2001) while others used it to describe progression through aspects of the health service (Singleton 2006; Teel & Carson 2003). A final group used journey to describe the nurse travelling with the patient as a supportive figure throughout the experience of ill health (Donovan & Mercer 2003; Edge 2006). The journey is an example of a metaphor which is familiar to the general public but has been adopted by healthcare literature to incorporate ideas about disease trajectory, progression and emotional support of the patient. It has become a widely understood metaphor which is, in these examples, used as 'shorthand' to quickly portray meaning to potential readers. The meaning is assumed, with the incorporation of this concept into the habitus of the field allowing these assumptions to be made.

Some authors used the metaphor more fully than simply making mention of it in the title and conclusion. For example, Glenn (2005) uses other language related to the journey theme which allows the concept of journey to permeate her short article (Glenn 2005). A number of papers use the metaphor of journey fully. These papers exploit the metaphor as a tool which helps to present data and make the data meaningful to the readers (Davis 2006; Halldorsdottir & Karlsdottir 1996; Johnston

2006; Simpson et al. 2005). These writers make more than passing reference to the idea of journey and use many references to aspects of journey as understood by lay people. For example, the route, travelling companions and even road rage are used to highlight aspects of the data presented. This chapter will consider similar aspects, as the metaphor of journey is used to explore and explain nurses' conceptualisation of dementia. Having contextualised the metaphor of journey within the study field, the term will now be defined more clearly before data is presented.

8.2.1 Defining 'Journey'

The widespread use of the metaphor of journey in healthcare literature reflects understanding of journey from the social world. The Oxford English Dictionary Online (2008) suggests that 'journey' may have a number of related meanings, two of which are noted below;

1. "A 'spell' or continued course of going or travelling, having its beginning and end in place or time, and thus viewed as a distinct whole; a march, ride, drive, or combination of these or other modes of progression to a certain more or less distant place, or extending over a certain distance or space of time.
2. the 'pilgrimage' or passage through life."

(Oxford English Dictionary Online accessed 08/11/08)

The first of these two definitions is commonly used and understood. The definition encapsulates some degree of certainty either about the destination of the trip or the duration of travelling. These are aspects of journey which will be discussed in terms of the data in the following pages. The second definition is interesting inasmuch as it

brings into common parlance some ideas developed from cultural and religious history. The view of a Christian life being a journey back to God or a pilgrimage to Heaven and eternal rest have been commonplace in Christian writing and have influenced aspects of the social world (Cole 1992). The Pilgrims who reached New England in the 1620s undertook a momentous journey, both in terms of travel and also in religious terms, as Protestant Christian thinking became embedded in the culture of their new homeland. These ideals influence aspects of culture; for example, views of aging can be related to Christian ideas about life being a journey from sin to salvation (Cole 1992). The two definitions of journey outlined form a backdrop to the exploration of the data generated by nurses who conceptualise dementia in terms of journey.

8.3 Conceptualising Dementia as a Journey

The data presented in this chapter illustrate two rather different ideas about conceptualising dementia as a journey. These ways of conceptualising dementia both include ideas about movement and progression but their end points are so different as to make them almost oppositional. Juxtaposing these two dementia journeys facilitates discussion of the contrasts and similarities between them and the important implications that these have for care practice.

The nurses talked about dementia as a journey in two main ways. Firstly, a number of the nurses considered dementia to be the individual's final journey and talked about the inevitability of death as the end point of the journey. This view has important implications for care, as it leads to discussions about palliative approaches to care for this group of patients. In most of the mental health areas included in the study, this idea was supported while most general nurses considered the idea preposterous. Data relating to this discussion and structural aspects of the care settings will be presented in the pages which follow.

Secondly, many nurses talked about the progression of dementia and the journey that the patients make but were unable to conceptualise the end point of the journey. Some did paint a picture of the journey's end point as a black or unknown place. Furthermore, many of the 'landmarks' of the journey in terms of symptoms were not recognised or connected, by the nurses, to dementia. This journey into the unknown raises some issues both for the nurses and patient care which will be addressed later in this chapter. Data will be presented in support of both conceptualisations of dementia as a journey and will be followed by discussion about care in relation to each dementia journey.

The idea of journey inevitably involves a destination. The destination may be planned or a mystery tour may take the traveller to an unknown destination. Routes to the destination may vary and different amounts of time may be required for individuals to make each stage of the journey. A journey may be a very personal endeavour or may be undertaken in the company of others. The metaphor of a journey is used to chart an individual's progress through ill health. These journeys, like those made by travellers, include a mixture of different routes, timeframes, experiences and ultimate destinations. Individual journeys are indeed individual and no two experiences of ill health are identical in the same way, as no two experiences of the same road travelled are identical. The nurse witnesses the journeys made by patients in his/her care. This position allows the nurse an insight into the journeys made by individual patients and, over time, allows the nurse to develop ideas about conditions more generally. He/she develops an insight into the journey as a whole and can conceptualise it as a 'distinct entity' as described in the Oxford dictionary definition of journey given above. The data presented in this chapter consider the ideas of journey and destination. Destination or the journey's end point is the key difference between the two ways in which nurses used the metaphor of journey. The nurses display very different ideas about the ultimate progression of dementia, with some seeing the end point as death while others could envisage no end point at all. An awareness of the various potential outcomes associated with a diagnosis contributes to the nurse's overall picture of a condition. Despite individual responses

to care and treatment which make each person different, a general picture incorporating experiences and education would, typically, include at least a blurred picture of the end point. However, while some nurses had ideas, others appeared unsure or had not considered much beyond initial symptoms. The juxtaposition of data portraying dementia as a terminal illness, with data which display a distinct lack of awareness of any end point, serves to highlight the mixed conceptualisation of dementia and must also raise questions about the quality and style of care for dementia patients.

8.4 A Final Journey

Some of the participating nurses considered dementia to be a diagnosis which would lead to death. However, the nurses who expressed this opinion were all from mental health areas, with the exception of Ava who was from a medical ward. Ava expressed clear views about the progression of symptoms of dementia and the potential for death to be the outcome. The following excerpt demonstrates how serious she considers the potential progression to be and how, in the face of her colleagues' protests, she argues her case. Her final statement was greeted with silence round the table and some discomfort, which suggested that Ava had exposed an issue which her colleagues did not feel comfortable with but could not challenge;

Ava: I think that a lot of relatives don't understand, cause dementia's confused with generally just getting old and I actually, I haven't personally done it, but I've overheard other nurses explain to their patients that what is happening to their relative is the disease process and that they won't get any better. I think that is something, people think they might get a bit better and you have to confront the fact that they're actually going to get worse. I think in the community dementia's looked on as not, maybe not as serious as it really is. Maybe even as slightly funny or, like in Eastenders just now they've got the Granny with dementia and (giggles)

Catherine: Oh yeh,

Ava: Alfie Moon's Mother ...

Helen: Oh, she's really, uh huh, she's really quite cute.

Ava: Just a bit cuckoo, now she's getting married, och it's all It's a romanticising of it. In reality she'll lose her ability and her continence and (interrupted)

Helen: But that doesn't happen to everyone with dementia does it?

Mary: No, it doesn't. (quietly – muttering)

Ava: Well, well I think it does. (indignant)

Helen: But, well no it differs. You get, with Alzheimer's if they're diagnosed and then they get treated for Alzheimer's and they do get progressively worse but there's other dementias that ... don't. They could be pleasantly confused.

Ava: Oh yes, they could be pleasantly confused. But (interrupted)

Helen: And remain so.

Ava: Well, as I understand it, it is degeneration of your brain so obviously other things are going to go. I mean, I suppose it's like anything else, the rate of progression (interrupted)

Helen: Well, but other things go anyway don't they? (laughing)

Ava: Uh huh, well yes, I mean you might, you might die first. I suppose there's more of it about because people live longer but ... I don't think it's a good argument. I don't, I think it's quite hard to be optimistic to a relative or the patient once they've had that diagnosis on the CT scan. I mean, it's, I see it as a terminal diagnosis (RN).

Other nurses in this group, such as Helen, were aware of the possibility of death but considered the time frames to be too long for death to be part of their picture of dementia;

Helen: I suppose we know with dementia if they could live, well quite a while longer. It doesn't seem as serious as ...cancer. (RN)

Ava's remarks shocked her colleagues and did not represent the prevailing view in her place of work. However, nurses working in mental health areas understood death to be part of the dementia diagnosis, as can be seen from the following extract;

Lauren: Dementia just totally changes the person as they were and it's very distressing for everybody and I think that that's including the nurses and the relatives obviously know the patient from before, obviously. And it's not an illness I would wish to have. And it can be quite frightening because it can happen to anybody and, you do become acutely aware of watching your own relatives. So it has a wide aspect. It can happen to anybody. It does happen to anybody and there's just no cure to it. The only end is death (MH).

SJR: Do you think nurses are aware that you can die from it?

Steven: Me, I wasn't even really that aware that you could die from it. Although they do say that you can die from it, you know when you're doing your training, it doesn't actually really sink in until you work in a dementia ward and come across a bereavement situation. Then it really sinks in that this really is something that is terminal and what you're really doing is palliative care. Until then, me, you're going around and you're too kind of caught up in all the physical care and the psychological care, that it's not really at the forefront of your mind (MH).

Both Lauren and Steven worked in mental health continuing care environments. Their comments were typical of those who work in these areas and had a marked effect on the care which is given to patients. Steven remarked that the care given to patients could be called 'palliative care'. This was a common belief among mental health nurses and was clearly related to their care. The care of patients dying of dementia was seen, by these nurses, as very specialist care. Moira gives some insight into her work caring for people with dementia over long periods of time until their eventual death.

Moira: We've got a lady just now been here 10 years and they come in and they are talking, maybe not terribly well, but, that slowly goes down hill until there's nothing at all and I find that more distressing. Cause you have a good communication with them, good conversation with them and then it deteriorates until there's nothing. I find that quite sad.

SJR: So the fact that the patient's going to deteriorate is part of the way you know this is going to progress...

Moira: Isn't that sad, because it's not like you'd be in a general ward where people might go out feeling better. You're not going to get better here. We're really, it's just really just loving, tender care really for them here, as long as they're here. And I think the care has to be specialist for that reason.

SJR: Yeah, it's a very specialist service I think...(interrupted)

Moira: Yes, very much so (MH).

Three points emerge from Moira's account. Firstly, she recounts her interaction with an individual over a long period of time and the sadness which she feels in watching the individual deteriorate 'until there's nothing'. This poignant account encapsulates much of what Moira experiences in her work and must colour her vision of dementia. The commitment shown by nurses in these areas and the emotional investment made by them was a striking feature of observation in these settings. As a nurse myself, this commitment was not something that I recognised from my own practice in more acute areas. The bond between nurse and patient was qualitatively different to the relationships formed in other settings. Journey was an integral part of that relationship as the communication from early in the relationship shapes the interaction at a later stage when communication declines. Williams and Keady (2008) highlight this idea in their discussion of 'bridging' in late stage Parkinson's disease. They describe three stages whereby an individual adjusts to life with late stage Parkinson's. Initial foundations for the bridging process are formed through 'building on the past', a complex gathering of information and relationship formation based on past events, biography and past relationships. Thereafter, individuals and their carers form bridges which allow them to move from the foundations of the past to deal with the present and consider the future. This longitudinal study followed 13

individuals and their family carers (Williams & Keady 2008). While the findings of this study could not be generalised to the relationship between nurse and patient, the foundation stage may be considered to have similarities. For example, Lauren talked about finding the individual's personality in order to form a true relationship with them;

Lauren: The entire person's personality, just everything about who they were alters virtually and one of the things you like to try and do is find the person that they were. You know, retrace steps back down the path. Sometimes they don't change as much but you have them, placid man who would never have said boo to a goose you know, who was just a lovely gentleman, a real gentleman, who now will well knock lumps out of us, all the time.

SJR: And it's terribly out of character.

Lauren: Yes, and that is, and will also strike their partner or, which again they would never have done before. Where they would never have sworn in front of a lady before they will now use the most obscene language. So it's the whole being, the whole being, virtually down to the soul that's changed. It's individual to every patient. You have to go back to get to know who they really were, so you care for the real person. (MH)

Nurses in long term care work with patients and families over a long period of time and build relationships, which then shape the future care of those individuals. This process was assisted by the structures and cultures of the long stay wards. Staffing was chronically poor but, while junior staff turnover was high, senior staff nurses tended to stay for long periods. This meant that there was a great deal of consistency of approach over time. Despite the structural issues raised by poor staffing, the habitus of the ward supported the forming of relationships. Staff were encouraged to spend time with individuals and their families and find out information which would be of benefit to the individual's care at a later date. This process was given priority in the long stay settings. This reflected the priorities of the setting, the focus on dementia and awareness of the disease trajectories. Furthermore, the distribution of capital was such that information about an individual's likes and dislikes had value

attached to it, whereas similar information in an acute medical setting would have been considered trivial.

Secondly, Moira talks in simple terms about caring for people until their death. There is no question that those in her care will remain there until they die and for many, that will be a long period of time. This long trajectory sets end stage dementia apart from other conditions requiring palliative care in which the 'end stage' is usually less drawn out. Palliative care is often connected with malignancies where it is unusual for the final, very dependent state, when an individual has limited awareness and is unable to communicate, to last for extended periods of time. In dementia care, it is not uncommon for this stage to last many years and in the study wards there were examples of individuals who had lived in these states for more than ten years. Palliative approaches to care will be discussed later in this chapter. However, Moira's contribution highlights the fact that her conceptualisation of dementia is formed against a backdrop of the disease trajectory and the knowledge that death will be the end point or destination of the dementia journey.

Finally, Moira stresses the specialist nature of the service provided in continuing care settings. This mirrors the commonly held view that continuing care of older people is the poor relation of more acute medical or psychiatric areas. The capital associated with acute areas is linked to the complex nature of the work, the need for speedy decision making and for expertise and education to prepare an individual for work in the acute area. In contrast, relatively little capital is associated with the slower pace and less technically challenging continuing care areas. Nurses are required to provide a great deal of hands on care to patients who, in many cases, are dependent on the nurse for every aspect of their daily life. Hard physical work is viewed less positively by society than challenging intellectual pursuits. Furthermore, the ward area is often distasteful, with patients behaving in ways which are not acceptable in wider society. For example, adults crawling on the floor, undressing, shouting and crying loudly are all aspects of the wards recorded in field notes and, generally, unacceptable in the

world outside the hospital. These very negative images of the ward area are in direct contrast to Moira's remarks. She views the care that she gives as specialist. Her remarks could be seen as a way of hitting back at these negative images in an attempt to enhance the image of nurses in this area. She could, of course, be promoting a view of her expertise in order to impress me as a researcher or to shift the balance of power within the field. Moira was, however, not alone in considering the work specialist. Lauren also uses language similar to Moira in describing her experiences of dementia care;

SJR: Do you think the nurses all actually take on board that somebody might die from this?

Lauren: Oh yes, oh yes.

SJR: That's interesting cause that's not been the case everywhere I've been. And there's been quite a number who, when I've suggested that, have asked if it's possible, which is interesting.

Lauren: But then this is a, this is an Alzheimer's and dementia place. This is a specific ward that specialises in this care.

SJR: So this is your expert area. It's what you do.

Lauren: Yeah. So we are well aware that given the end for these people is death and is no better. It's just a gradual deterioration.

SJR: Do you see what you do as palliative care?

Lauren: Yes it is in some ways. Yes I've done, I've done, cancer special nursing and it is... I mean at all times you were trying to make the patient as comfortable as possible which is it.

SJR: Yes, central isn't it to the whole palliative care philosophy.

Lauren: Yes. Even going along to feeling them and feeling their arms to see if they're cold. So you then go and put a cardigan on them. They can't come to you and ask for a cardigan. Em, so you have to, as I said, maintain their body temperature (MH).

The extracts from Moira and Lauren's interviews show their understanding of dementia potentially leading to death. They chart the decline of individuals' abilities

over long periods of time and allude to their own interaction with this process. Finally, they promote the view that the care of patients over this period is specialist and contrasts that with the ‘basic care’ label which is often attached to work with this group of patients. This label will be discussed further in the following section on care.

The data presented so far suggest that nurses working in mental health areas, where people are cared for over long periods of time, are united in considering dementia to be a series of conditions which lead to death and the care of dementia patients as palliative care. These nurses see their patients’ journey leading to an inevitable death and use their vision of this destination to shape the care of patients embarking on that journey. In their discussion of dementia as a journey, Small et al. (2007) note that;

“Physical death of a person with dementia is an important part of the experience of the journey for family members. The nature of the death may colour how the whole journey is then regarded in retrospect (p35).”

From experience of working in long stay settings, nurses may have the retrospective view which Small et al. (2007) suggest is important in shaping a view of the dementia journey. This view of the journey’s end contributed to their conceptualisation of the dementia journey as a whole. Many other nurses did not share this vision and, indeed, many offered views which directly oppose the views of the nurses highlighted thus far. These views will be considered in the second half of this chapter. However, considering the dementia journey to lead to death is a vision which shapes the care of individuals and has wide ranging implications for practice. The next section will consider care in detail. Palliative care will be discussed in the light of the view of dementia as a terminal illness. Specific aspects of dementia care will be highlighted and discussed in relation to palliative approaches to care. Finally,

questions about palliative approaches to care will be raised in order to provide a backdrop to the second half of this chapter.

8.4.1 Palliative Care

The issue of palliative care for people with dementia has been raised in the literature for a number of years. However, literature suggests that many older people dying of dementia do not receive formal palliative care (Birch & Draper 2008; Mitchell 2007). Palliative care is defined as follows;

“Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount.

Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital.

Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.”

(European Association for Palliative Care 2008 accessed 05/11/08)

This definition encompasses the care of those people whose condition can not be cured. This moves away from early definitions which focussed heavily on cancer care, the last days of life and terminal phases of conditions (Birch & Draper 2008). The National Council for Palliative Care and Government health policy (Department of Health 2001; Department of Health 2006) recognise the need for palliative care for those who are not at immediate risk of death but have a prognosis of months or years. While this is recognised, it is also noted that many people in this group have difficulty accessing palliative care services (National Council for Palliative Care

2007). Dementia could be fitted into this outline as it is now recognised by many as progressive and potentially fatal (Lloyd-Williams & Payne 2002; Shuster 2000). However, while this prognosis is factually accurate, a number of people do not recognise dementia as life threatening (Ahronheim et al. 1998; Mitchell et al. 2004). These are findings which are reflected in the responses of nurses in this study. Difficulties with diagnosis and poor prognostic information limit the ease with which the palliative approach can be implemented in practice (Mitchell 2007; Rozzini et al. 2007). This is particularly true in clinical areas where access to palliative care is determined by the predicted length of remaining life. For example, in the USA, funding may only be made available for such care in cases where an individual has six months or less to live (Rozzini et al. 2007). Palliative care is often organised through specialist teams within the hospital. An audit of these services in 1996 showed that the majority of teams' remits did not encompass dementia (Lloyd-Williams 1996). Indeed, palliative care services are recognised to be underused by older people generally, and those with dementia specifically (Addington-Hall & Higginson 2001). Data presented in the previous chapters demonstrate that nurses are reluctant to use the term dementia and have limited knowledge of the scope or trajectory of dementing conditions. Furthermore, a significant number of nurses participating in this study did not know that death was a potential outcome of dementia. These issues all stand in the way of the implementation of palliative care with dementia patients.

Many of the difficulties associated with accepting palliative care as an appropriate approach to dementia care, lie with the extensive and unpredictable time from diagnosis to eventual death. The age profile of dementia patients means that many will not die from dementia, but will die from other conditions such as heart disease, sepsis or stroke. The lengthy period between diagnosis and death and the coexistence of other medical conditions in already elderly patients, lead to the fragmentation and polarisation of care. Units throughout the hospital care for people who have dementia and a coexisting medical condition. In many cases, the dementia is not the focus of the patient's care but is, simply, an adjunct to the broken bone, underlying

respiratory condition, heart failure or diabetes which was the primary reason for hospital admission. Those in the early stages of dementia are often found in this wide variety of clinical settings, in short stay assessment units or in general medical wards. Others, who have advanced dementia, are often cared for in long stay mental health units or in private nursing homes which were outwith the scope of this study. Nurses, therefore, rarely see both early and end stage dementia patients within their ward areas and, as such, have limited overviews of the trajectory of dementing illness. This structural division in the field means that the nurses' experiences are different and the habitus of their workplace is, consequently, also different with different guiding principles and acceptable practices.

The data show that most of the nurses from long stay wards recognised palliative approaches in the care that they give to their patients. The nurses from general medical wards, who could not consider such approaches, had little or no experience of end stage dementia. The habitus of the workplaces reflects the different aims and theoretical underpinnings of the wards. Palliative approaches to care are deemed to be appropriate and desirable in long stay areas, while the nurses working in the more acute general medical areas and in mental health assessment units, found these approaches to be inappropriate for their client group. While the culture and aims of the workplace may be part of the reason for this major difference in approach to care, another reason may lie in the nurses' understandings of palliative care and how it might be best used in dementia care.

The definition of palliative care given earlier in this chapter is a broad definition covering pain and symptom control, as well as spiritual and psychological problems. The study nurses, however, demonstrated rather limited views of hospital based palliative care. They talked about specialist palliative care nurses adjusting pain medication and helping with complicated discharges of dying patients. Melanie and Alison, who worked in different hospitals, indicated their vision of palliative care within the study field;

SJR: One of the nurses I spoke to last week suggested that the dementia care that she provides she thinks of very much as palliative care because she realises that this group of patients could die from this condition and they're deteriorating and so she sees it in that way. Does that make sense to you?

Melanie: I think that's extreme cause you wouldn't treat somebody if he comes in with cardiac trouble, you know with palliative care team, like you know if it was the end stages of cardiac failure. Like there's still quality of life there. It's really pain and Morphine pumps they do. Getting folk home to die, you know (RN).

SJR: And palliative care? Would that be something you would ever consider for somebody with dementia?

Alison: No. Normally just cancer patients.

SJR: Yeah? It's interesting because there's quite a lot of literature around now about palliative care for people with dementia and I think it's a big culture change isn't it, to change from thinking of palliative care in terms of only cancer.

Alison: Here the team just deal with cancer, I think... I think so. (RN).

These nurses' focussed on aspects of palliative care which are most often needed in the last days and weeks of life. Discharging people home to die and arranging Morphine pumps represents a very limited view of palliative care although it may, indeed, reflect the view that nurses working in general ward areas have of the palliative care team. It also reflects the focus of some of the literature around dementia and palliative care, which deals specifically with medication use and clinical interventions at the end of life (Holmes et al. 2008; Lorenz et al. 2008). This focus on treatment of individual symptoms leaves a gap in the literature surrounding an all encompassing approach to care (Small et al. 2007). Palliative care was not the focus of this study and data collected in this area do not explore the subject in any great depth. However, the nurses' limited view of the remit of the hospital palliative care team may contribute to the difficulty that many nurses had in understanding the potential for palliative care with dementia patients. Those who did indicate that their

role encompassed palliative care, such as Lauren who was introduced earlier in the chapter, also tended to have slightly limited definitions of palliative care. Lauren summed up her care as ‘keeping people comfortable’ but only described physical aspects of this despite working in a mental health setting.

Notions of palliative care related to pain relief and care in the days immediately before death are important for some individuals and useful in certain care settings. However, using the principles of palliative care to shape the nursing of patients over a longer period of time may be more useful in the field of inpatient dementia care. This longer term approach relies on awareness, at an earlier stage, that the individual may die from dementia. Data from this study suggest that this premise may challenge nurses’ existing conceptualisations of dementia. However, the potential benefits of a longer term palliative approach to care may be significant and are worth exploring despite this underlying difficulty. As outlined earlier in this chapter, literature on palliative care and dementia tends to focus on the period shortly before death. Finding literature which discussed a more long term approach to palliative care was challenging, not least because the terminology was not standardised across the literature. For example, authors use terms such as ‘upstream palliative care’ and ‘long term’ palliative care was not recognised. Upstream palliative care is a concept from the USA which was originally designed for individuals living in ‘assisted living residencies’ (Mitty & Flores 2008; Mitty 2004). The approach uses some of the pillars of palliative care, namely symptom management, interdisciplinary working and user involvement, to shape the planning of care for an individual. Mitty focuses on organisational and accountability issues in her papers, highlighting who would be responsible for each step of the process and outlining how planning in advance can ensure that care responds to the needs and wishes of the individual. While these papers raise many issues which are not applicable to the field of inpatient dementia care as described in this study, the combination of dementia care and palliative care is a useful template for further exploration of the literature.

Principles of person centred care (Kitwood 1993; Kitwood 1997) were outlined in chapter two and form the backdrop to what is widely regarded as high quality dementia care. In a recent papers, which aims to highlight best practice in dementia care, Downs (2006) and Small (2007) combine the approaches of palliative and person centred care. They outline the difficulties associated with unnecessarily interventionist care which does 'too much', and also the deficiencies and neglect evident when care offers 'too little' to those with dementia. Through his comparison of the two approaches, Small demonstrates how palliative and person centred care have overlapping aims in terms of addressing physical, emotional, spiritual and social aspects of an individual's life, involving patient and family, using an interdisciplinary approach and, crucially, prioritising the individual in the care planning process (Small 2007). Palliative and person centred care can, Small argues, learn from each other. Combining the two approaches would bring together skills of communicating with those who have no verbal abilities, working with cognitive deficits and challenging behaviour, restricting unnecessary interventions and including family and caregivers. The result could be an approach to care which could span the long periods of time which may exist for a dementia sufferer, while taking account of the challenges of living with a life changing and potentially life threatening condition. This combination approach could be used, both in acute and long stay settings, and has the potential to guide nurses in their care and care planning for people with dementia at each stage of their dementia journey.

Further to this combination of palliative care and person centred dementia care suggested by Small (2007) and also framed by Downs (2006), the very beginnings of another variation on traditional palliative care emerge from this study data. The data show that nurses, particularly those in long stay settings, felt strongly about the environment in which their patients live, the decisions that they could make or contribute to and the elongated relationships that form between this group of patients and their nurses. While these concerns emerge in response to the declines evident in dementia, they are socially focussed rather than typically medical in their nature. More medical aspects of care were mentioned by nurses too; for example, use of

medication and management of agitation. However, the nurses' time, in longer stay settings, was dedicated, predominantly, to the care of social aspects of the lives of individuals and their families. Dementia has been described as a social death involving the diminishment of personal traits which shape an individual's personality and the 'loss of self' (Cohen & Eisendorfer 1986; Cohen & Eisendorfer 2002; Sweeting & Gilhooley 1997). An individual's sense of self is central to the work of Kitwood and the theory of person centred care. The belief that the internal sense of self remains intact in advanced dementia (Sabat & Harre 1992), while the external portrayal of self is damaged through interaction with the social world and malignant social psychology in the face of cognitive decline (Kitwood 1990), has led to the development of person centred care. This development was outlined in more detail in chapter two and used to discuss memory in chapter six. The importance of social interaction in shaping both the progression of dementia and in reinforcing an individual's sense of self are recognised as important aspects of dementia care (Golander & Raz 1996). With this in mind, the nurses' focus on social concerns rather than, typically, medical concerns are supported by academic literature within the study field and, as such, carry significant capital which gives social aspects of care more authority in the dementia care arena than would might be allowed in other clinical areas. This may, in part, explain the emergence of the social focus among nurses in long stay dementia care areas and not in the more acute medical or psychiatric settings where there are fewer dementia specific care aims.

8.4.1.1 Social Palliation?

The social issues of environment, decision making and long term nurse-patient relationships were all considered by the nurses in the light of the individuals' dementia journey. This group of nurses used the journey metaphor to describe their own roles in travelling with the patient and also in improving the environment through which the individual travelled. The nurses considered the dementia journey would end with death and highlighted these, mainly social, concerns as vitally important along the way. Therefore, the idea of social palliation emerges which

supports the individual in their journey towards social death. Sweeting and Gilhooley (1997) describe social death in individuals with dementia and note that it usually occurs sometime prior to the biological death. They highlight three groups who are at risk of succumbing to social death prior to their biological demise; namely, the very old, those with lengthy fatal illnesses and those who are losing their essential personhood through dementia or other damage (Sweeting & Gilhooley 1992). These individuals effectively withdraw from the social world in advance of death. While the timeframe of this withdrawal may be difficult to assess, one defining moment suggested by Sweeting and Gilhooley is the failure to recognise relatives. Social death is only one way of describing the process which is evident in advanced dementia and this would not be upheld by everyone caring for people with dementia. Indeed, some of the relatives in Sweeting's study did not support the view. While social death may overstate the process, social aspects of the progression and eventual death of individuals with dementia are recognised more widely and, as such, palliative care which is focussed on social issues, may be very appropriate in this group of patients. The theoretical aspects of social palliation may sit comfortably both within the dementia literature and with the data emerging from this study. However, the theory can only be operationalised if it works in practice. The data presented in the following sections highlight the social issues raised by nurses and consider the use of the palliative approaches outlined in shaping nursing care.

8.4.2 Palliative Approaches to Care in Practice

In the following section, data are presented in support of the nurses' strongly held views about the ward environment, decision making and long term nurse-patient relationships. These data are presented with a view to demonstrating how palliative approaches can or could guide care for this group of patients. Firstly, the nurses were very concerned with the environment in which their patients lived. The environment of the ward was an issue raised by the nurses in connection with all aspects of dementia and patient care. Chapter seven outlined ways in which environment could be related to confusion and, throughout the data, the ways in which the environment contributed to the organisation of care were clearly seen. Environment was also

considered by the nurses to be an important factor in relation to the dementia journey. Many nurses working in acute or rehabilitation areas, both within medical or mental health settings, talked about the inappropriateness of the physical environment for dementia care. They highlighted the lack of privacy and use of communal facilities, repetitive décor which leads to disorientation and the physical presence of technical equipment, all contributing to an environment which was not conducive to the care of individuals with dementia. However, those working in long stay units also made considerable comment about the ward environment and these remarks could often be related to ideas about journey and palliative care. None of the wards were purpose built and the physical environment was often problematic in the first instance. For example, many of the wards had long corridors with dead ends and little natural light. This was difficult for those who wandered, as they tended to congregate in the dark corners at the end of the corridors or at the ward door. The enclosed nature of the ward area was claustrophobic and this, along with the layout and the locked ward door, contributed to a charged atmosphere which could become rather frantic as individuals paced. There was no accessible outside space attached to any of the study wards.

The following extract highlights some of the difficulties which were experienced by nurses in each of the long stay settings;

Simon: When you actually get into the ward you think ...

Felicity: Who would want to come here?

Simon: What's going on here? This is the long term. This should be the nicest of the nice. This should be people's homes and it is staggering. This place is the end of their road you know. It should be nice. It's a big part of the problem. These people shuffle around the corridors within the wards. L shaped wards, there's nothing in it, the same blank walls, linoleum floor, there's nothing for them to do. Ehh, you know they can literally get up and sit in a chair and sit there and go for a meal and sit there and go for a meal and go to bed.

Felicity: I mean the guys in our ward it doesn't matter to them what the weather's like. Cause, I mean, they can't get out, they're 2 flights up, half of them, you know, they get out once in a blue moon and it's onto a minibus and round about because they're just... (shrugs)

Simon: I mean there's patients on our ward who haven't breathed fresh air for years and years and years!

Felicity: Yeh, in an ideal world you'd have a little veranda or garden that you could take them out, even if they were in wheelchairs and sit them outside. And the ones who're wanderers, I reckon a lot of our agitation would decrease tremendously if we just had a larger and more pleasant and realistic environment. Like the day hospital garden or something like that. If we'd had ground floor access to that as well and they could wander about there, potter about maybe, do more things like that to channel their agitation.

Simon: As I say, the majority of problems we have tend to be as a result of physical things, the layout of the ward, the lack of furniture, the lack of space to separate people, so that they've got several areas to meet in rather than one big sitting room. The majority of our problems seem to be caused by the ward itself. (MH)

The ward layout, overuse of communal areas and lack of outside space were all regarded by these nurses as significant problems in this long stay setting. The structural difficulties had far reaching implications for care and for the quality of the experience of the patients. This is a phenomenon which is recognised, both in dementia literature and further afield (Bachelard 1994; Judd et al. 1998).

Simon's remark that the long stay environment 'should be the nicest of the nice' underlines the importance which he places on the environment in terms of shaping the patient experience. His remarks are also in keeping with the thoughts and actions of nurses in other similar clinical settings who put considerable personal time and effort into improving décor in the ward areas. This effort to improve the quality of patients' lives reflects the positive philosophies of palliative and person centred care, in emphasising the importance of enhancing quality of life. Bedrooms were decorated in a variety of colour schemes and funds were raised for bed linen which

complimented each room's design. Furthermore, murals were painted onto the walls of the long ward corridors to give dead end spaces new purpose. For example, a washing line with fluttering washing was painted in one corridor area, creating a focus for many of the women who could identify with the image and were reassured by feeling affinity with the surroundings. Similarly, windows with views of distant hills and seascapes were painted in the narrow passageways, allowing a feeling of space and a bus stop mural filled the space, where a number of patients tended to wait in a dead end corridor. The considerable effort required to design, paint and raise funds for these innovations reflected a huge commitment on the part of nurses, not just to the ward and its residents but to the ideals which these decorative changes represent. These projects and Simon's wish that the environment should be more pleasant for patients, demonstrate the nurses' desire to provide comfortable surroundings which put their patients at ease and enhance quality of life. There was also a focus on social aspects of life in the décor, with the use of symbols from the social world, such as the bus stop and washing line, to provide reminders of social roles and structures from the world outside the hospital ward. This use of social symbols is in keeping with the reinforcement of self, which is an important aspect of person centred care but also reflects the potential role of social palliation, specifically in dementia care.

The nurses also felt strongly about decision making and their approach to this important aspect of care reflects issues arising from palliative and person centred care, along with dominant paradigms from the social world. Decision making in long term care often takes place against the backdrop of a long term nurse-patient relationship. The nurse will also know family and friends who are important in the individual's life and can take account of opinions from each of these people, as well as the patient. However, in more acute areas, the decisions which are made may be made more quickly and nurses may have less time to get to know significant others. These relationships are important aspects of the individual's social network and can be influential during the decision making process as outlined by Nolan et al. (2001 & 2002) in their work on relationship-centred care.

Planning ahead is important in dementia care, as decision making capability can decline over time. In the early stages, an individual can make independent decisions and plan ahead, making a note of any choices for the future, in order that his/her own wishes may be carried out, if the need arises. However, in order to be able to take advantage of this time for planning, the individual must have the opportunity to discuss the future and consider symptoms and care options which may be available to them. Data presented earlier in this thesis highlight the nurses' reluctance to use the word dementia and to think of the magnitude of dementing illness. The data also highlight gaps in their knowledge of progression. These factors significantly limit the nurses' capacity to facilitate advance care planning, when an individual may wish to do so. Palliative and person centred approaches both stress the need for an individual approach, focussing on the needs and desires of the individual and his/her family. Furthermore, these approaches take a positive view of life, through the enhancement of quality and the reduction of disruption caused by symptoms, wherever possible. Palliative care also regards death as a normal point of the lifespan, neither hastening nor postponing it, but being aware of the fact that this point will come.

The nurses working in long term care demonstrate an awareness of palliative approaches in their decision making, although decisions are still influenced by other dominant paradigms from the social world. For example, Lauren outlines some of the decisions which have to be made in her long stay ward;

Lauren: We have patients who have not got a swallowing reflex but we still are able, with a lot of coughing and spluttering, they can take in enough, well more than adequate nutrition and protein and calories. There was a patient that was on bed rest for a considerable amount of years and was just progressively getting worse in the eating and they spoke about putting up peg feeding and I believe that, the other side [surgical ward] that the surgeon wouldn't do it because he didn't feel he was maintaining the quality of life.

SJR: Ok. It's a very difficult dilemma isn't it?

Lauren: It was. The relatives have obviously a lot of choice. They're asked. I mean we don't put up IVs in this ward. We don't do any of that kind of intervention. One, if that intervention is needed they really have to go across to the other side [medical] because, the type of patients we have in here, it wouldn't be safe.

SJR: Yes you couldn't combine the two?

Lauren: No. it wouldn't be safe. We couldn't do the risk assessment you know.

SJR: Well are people not happy that their relatives stay here with the staff that they know, rather than move to another...

Lauren: Yes, definitely. They don't want that. But it must be difficult to, to decide when you stop, treatment you know. But what are we going to do? All we're going to do is if the patient's no longer swallowing and we put up an IV, what we're doing is prolonging the inevitable.(MH)

Lauren shows an awareness of quality of life in her outline of the decisions which are made on her ward. However, these decisions are limited by restriction on the treatment options available because of the dominance of risk in shaping decisions in health care. The risk of running intravenous fluids in a ward where people are generally severely confused and often display challenging behaviour, was deemed too serious to make that treatment possible. Risk was noted as a determinant of care in chapter six and is a powerful influence from the social world at large.

Lauren also touches on the role of family members in shaping decision making. This is a role which many nurses discussed. Some recognised the difficulties encountered by family members, for example;

Victoria: I think if you speak to relatives as well maybe it helps them to cope and understand, think of what's ahead. I mean sometimes they might think they're the only person going through this. Maybe there's no ideas about what's to come. I mean I'm no very up on groups and things that's going on but, there's maybe somewhere they can get a

wee bit help and assistance as well. Before we start asking what they want for their nearest and dearest. It's hard for them to know. I think it's very hard on relatives and I think relatives feel they have nowhere to turn to sometimes. Just have to carry on down the road with them, trying to keep things on track.(RN)

Andrea: I think the family feel a lot of responsibility. You know if they're adamant they want to go home. I think the family feel a lot of responsibility because they want them to go home but then they're thinking we're going to be left to support them here, you know. It's probably harder for the family because we can take a step back and be logical about it, you know, but families obviously can't and if their mother's sitting there saying I'm determined to go home then it's hard for them to say we no you can't go home. (RN)

Both nurses recognise the responsibility which families have and the tensions which can arise when planning for the future. Victoria once again uses the journey metaphor which is a reminder of how comfortable the nurses are with this terminology. Palliative care was not mentioned by nurses with regard to decision making in the acute or shorter stay areas. However, nurses in the long stay areas did use a palliative framework for decision making about assisted feeding, resuscitation and other medical interventions. The client groups involved were, largely, unable to participate in active decision making in these areas but were involved, wherever possible, to varying degrees. Notice was taken of individuals' preferences prior to their decline, although few had written advance directives or formal statements of wishes. This is an area where earlier implementation of palliative approaches could inform end stage decision making. Using a palliative framework at an earlier stage would allow individuals to consider some of the decisions that might face them and their families at a later stage. As outlined earlier in this chapter, the combination of palliative and person centred care could maintain a positive outlook, while working to enhance quality of life in the face of expected decline and eventual death.

8.4.3 Basic Care and Palliative Care

Before concluding this section on practical aspects of palliative care, the specific role of the nurses in long term care wards will be briefly discussed. For those who have never visited a long term ward, it is hard to imagine the day to day role of a nurse in that setting. Patients who live in inpatient settings often could not manage in other forms of residential accommodation because of complex health problems, challenging behaviour or severe end stage presentations. Some wander constantly while others are bed or chair bound. Some shout while others have no recognisable language and while some enjoy social interaction, the majority of those on the study wards found communication very difficult. Most of the patients in the wards where observation took place were incontinent and many needed help with feeding and dressing. This kind of care was referred to as 'basic care' by a number of the nurses. In terms of nursing care, the mechanics were indeed basic. There were no pieces of technical equipment, no complex recordings to make and most of the day was spent engaging in hands on care such as toileting, dressing and feeding. The work was physically hard and mentally draining, as individual patients were often unable to respond or did so in unorthodox ways. However, the nurses found their work pleasurable and many put in extra hours on a regular basis. The long stay dementia ward is often regarded as a 'Cinderella service', falling short of the complexity or acuity of acute psychiatry or general medical areas. The capital attached to 'basic care', as it was referred to, is far less than that attached to the more technical nurse's role. The social world recognises achievement in terms of technical ability and rewards these abilities through the distribution of capital. However, a different type of capital is assigned to those who are dedicated to a cause, through which they gain admiration and status by their commitment to a specific role or cause, despite the hardships which must be endured. This kind of appreciation and the status which goes with it, are very culturally dependent. The admiration of individuals who look after people with end stage dementia could be viewed in this way. In a social world in which older people are, generally, regarded negatively, cognitive function is highly regarded and socially appropriate behaviour and interaction are expected, people working with individuals who have end stage dementia, and, therefore, fall short in these areas of social expectation, are to be admired.

Basic care may be simple in its content but, in order to carry it out effectively and support the individual as part of a family, a skilled nurse will find many ways to stretch his/her role. This was explained by a Charge Nurse as follows;

Theresa: 'It's not shovelling tatties everyday'. Every minute of every day is different and involves being part of the life of the patient in your care. This is a deeply interpersonal relationship requiring every bit as much skill as observing the psychotic or suicidal patient. (MH)

Indeed, basic care could be regarded as every bit as complex as the most complicated intensive care nursing only using different skills. However, those nurses working in the long stay settings could be said to portray their work in a different way, in order to gain the capital which goes with looking after those who are dying. Describing their work as palliative care and their clinical areas as 'specialist' allows the nurses to gain both the capital associated with care of the dying and also with the role of a more specialist practitioner. This process may not be deliberate and these remarks are in no way intended to portray the nurses as dishonest. The analysis only serves to explain some of the influences on nursing practice and to explore the understandings and motivations which shape the nurses' work.

These brief examples show how palliative approaches could be beneficial in the care of individuals with dementia. Some of the participating nurses were comfortable with this approach, while others were not. Those nurses working in acute areas, rehabilitation and assessment or general medical wards did not currently use palliative approaches, an issue which will be discussed in the section which follows. Some nurses in those areas were aware of person-centred dementia care, although more were aware of the individualised care models which are more common in general medical areas. Nurses working in long stay areas did use a palliative care framework in their care. This was demonstrated by ways of considering decision making, the overall ethos of the wards and the environmental changes which were

made in some areas and discussed in others. Palliative care was portrayed by nurses as a specialist approach, which was being used within a specialised ward environment. This approach added capital to the care given and, in turn, raised the status of the nurses practising in this area. However, the culture of the two wards where observation took place, supports the nurses' assertions that their practice was informed by palliative care philosophies. Having considered both theoretical and practical implications of nurses considering the dementia journey to end with death, this chapter now moves on to highlight some of the difficulties raised by palliative dementia care.

8.4.4 Problems Associated with Palliative Approaches to Dementia Care

While palliative approaches to care may have the potential to meet the changing needs of individuals who are living with dementia and their families, there are also considerable challenges which need to be addressed. Firstly, chapters five and seven highlighted some difficulties with the diagnosis and recognition of dementia. Diagnostic uncertainty, non disclosure of diagnosis, poor recall of the diagnosis during history taking and reluctance on the part of nurses to recognise dementia were all highlighted as issues which prevent clear recognition of dementia. Furthermore, many of the nurses involved in this study had limited vision of the trajectory of dementing illness. This may indicate gaps in education but may also reflect the work experiences of the nurses who tended to care for patients at one or other end of the dementia spectrum and, therefore, develop little vision of the full spectrum. If both the diagnosis of dementia and then its progression are not part of the nurses' understanding of dementia, early intervention by nurses using a palliative approach to care, as outlined above, would not be possible. This lack of knowledge and the reluctance of nurses to recognise dementia, by using instead the language of confusion or memory to shape understandings, limit their practice in this regard.

A second and related issue lies with the disregard that many participating nurses had for the idea of palliative care in dementia nursing. This may be, in part, due to the issues outlined above, but may also reflect attitudes to the palliative care services within hospitals. Those nurses working in long stay areas were very clear in their vision of their work as palliative care. However, colleagues in shorter stay and more acute clinical settings, dismissed the idea of palliative care out of hand. In fairness to those nurses, the ideas put forward by myself during data collection were not fully formulated and my own tentative suggestions may, indeed, have sounded far from convincing! Data presented below, however, show a depth of negative feeling on this issue which might be difficult to break down. June highlights the influence of her workplace on her feelings about palliative care;

SJR: What? How do you feel about the idea of palliative care for people with dementia? Does it sound reasonable or does it sound a bit way out?

June: No, it sounds unreasonable. No it doesn't sound No way!

SJR: It's interesting just to see different people's reactions to it because some people probably those who don't, who wouldn't accept that you might die from this, have really rejected it and they've said oh no that's just a bit bizarre. But, I can see a place for it. I just wondered if it was something that sounded reasonable or not?

June: I think we would tend to have moved them on by the time if they were at that stage. I don't know (RN).

However, using a palliative approach to care and care planning or considering the social palliation outlined above, need not be the job of a palliative care specialist but should form part of the toolkit of a registered ward nurse working in this field. The cultural change needed to adopt this approach in acute medical, rehabilitation and assessment areas should not be underestimated. An interview with Susan, a progressive Charge Nurse who was working hard to set up a new acute medical unit focussing on admissions of older people with acute confusions and dementia, shows how much of a change this might be;

SJR: There was some who thought that it happened to a lot of old people and we were sort of getting towards it's part of normal ageing. Emm and there was one or two who thought of it kind of palliatively and this is something that was going to change this person's life forever and therefore we should be thinking in terms of quality of life and perhaps palliative approaches to care (Susan looks sceptical) which is maybe a big step? I don't know but that's quite ... (interrupted)

Susan: I think that's a huge step.

SJR: A bit drastic?

Susan: Eh, very yeh, Mm. Can't see it here. (RN)

Early palliative approaches would not suit every dementia patient and, like any other approach to care, would have to be discussed on an individual basis. Some individuals will not wish to consider dementia as a life changing or, potentially, life threatening diagnosis. The importance of individualised care was stressed in chapter six and this individualised approach must guide the interventions most appropriate to the patient and their family. Some will reject palliative approaches out of hand, whether social or more traditional, while, for others, a palliative approach may allow the most to be made of the time and function remaining. Palliative care was considered to be a 'huge step' by Susan in the excerpt above. This view may reflect her reluctance to consider the serious potential outcomes of dementia or may reflect her desire to maintain a positive approach to living with dementia. Palliative approaches may be considered negative because of the underlying focus on end of life issues and the familiarity of palliative care in end stage cancer care. However, it could be argued that some aspects of palliative care improve the individual's ability to live positively with dementia, by maximising the positive use of remaining time and function. Social palliation, as outlined above, may be able to do this as it facilitates the individual living within his/her social network. The underlying view of palliative approaches to care being for those who are likely to die imminently is challenged by the vision of social palliation. In order to make this work in the reality of the study field, education and practical strategies would need to be introduced to

the nurses, in order to take account of their current understandings about the trajectory of dementia, palliative care and living positively with dementia.

The nurses' conceptualisation of dementia as a final journey towards death raises the possibility of palliative approaches to care being appropriate for this group of patients. This section has outlined some aspects of palliative care, beginning with some definitions and ideas about palliative care generally, before moving on to some dementia specific points. Data were presented to show that the long term nature of the decline in dementia and the environment of the field were of particular concern to nurses. Decision making and ethical issues encountered while caring for an individual with dementia were also considered within a framework of palliative care. The idea of dementia being a social death was discussed and the potential for a new understanding of palliative care, which incorporates person centred dementia care and includes social palliation as a key component of care for this client group, was outlined. Finally, remarks were made about basic care and some of the difficulties associated with palliative approaches to care, were highlighted. The remainder of this chapter returns to the metaphor of journey, following the path of those nurses who do not believe that dementia leads to death.

8.5 Journey: Destination Unknown

The language used to discuss dementia is interesting and demonstrates how some nurses conceptualise the process of dementing. The theme of a journey is recurring although it is not always mentioned as a specific word. Nurses talk about their patients leaving this world and going to another place as part of the process of dementing. For example, Simon describes patients in his ward;

Simon: Because the patients we've got, the majority don't even know they're demented because they're that severely demented that its gone past the confusion and forgetfulness stage and they've crossed into

whatever world they've crossed into almost. Ehh so as long as they're happy they don't care, they're not aware of it (MH).

In his description, the patients have left this world and have moved into another place. It is clear from his words that this world is unknown to him. He does not describe the 'other world' in negative terms. Indeed, he mentions that the patients can still be happy. He notes that the patients' awareness is diminished and therefore happiness may result from pleasures or comforts known in our world and simply not upset by 'crossing into' the other place. Samantha and Louise also discuss people being in another world;

Samantha: From a personal point of view my grandfather he, remained intact in his brain, but he became really badly physically disabled and that was more distressing to him as opposed to being physically able and completely away with it, but quite happy because they're just away in their own wee world. Em, but then again there's other times when they quite often have to go through this phase of realising that they're losing it and having sort of flash-backs and that's often very upsetting. I think if anybody has actually got a real dementia they're quite often quite happy. They're just in their own wee world.

SJR: Would others agree with that or?

Louise: I think it's very difficult for the families of people having to cope with them. They may be quite happy in their world but they're not always happy (RN).

The idea of going somewhere else and being happy seems to be tied together for the nurses. This may be a defence against anxiety on the part of the nurse who, naturally, finds it less distressing to imagine the patient happy and contented in another place, than confused and disturbed in their present location. Furthermore, the idea of journey is rather curtailed in the nurses' accounts. People cross from one place to another in a manner more 'black and white' than varying shades of grey. Occasional

references retain elements of the motion associated with the journey idea, for example;

Simon: Whereas my ward's longer term. Eh, it's sort of we're keeping them safe, clean, fed and that's 90% of what we do for them a lot of the time because mental health wise they're too far along the path of dementia. I mean, even just any kind of communication of any kind of rational type is difficult at times. If you can't, if you've got limited communication with them it's then hard to, to do anything else apart from that so. Keeping a safe environment tends to be the main, you know (MH)

The ultimate 'destination' on the journey that is dementia seems to be problematic for many of the nurses who contributed to this study. There are a number of issues which contribute to this lack of clarity on the part of the nurses. Firstly, the death certificate reporting of death from dementing illness is very variable and is blurred by individual medical staff and by the age of the patient. This is highlighted by Felicity and her colleagues;

Felicity: I don't think nurses realise that dementia's a terminal illness, it's been categorised as. Certainly in our ward you know, relatives ask 'how long are they going to be here' and your like, well really they're here until, unfortunately the end does come. And they're like dementia won't kill them, what will it be, will it be a chest infection or, well it is a terminal illness you know.

Joanne: I think there's a bit of a bone of contention in the medical staff. Some of the medical staff will agree to write it on the death certificate as primary cause of death and others won't you know. The jury's still out on that one I'm pretty sure. Yeh, it is a terminal illness but I don't think a lot of people are made aware of that just now.

SJR: Do you think nurses are aware of that when they're planning what (interrupted)

Joanne: I think we're becoming more aware.

Pat: But they're geriatric anyway so, you know. (no responses around the table) (MH)

Secondly, some nurses do not think of dementia as being a serious diagnosis and, much like one of the nurses who inspired this study, considered the progression of symptoms to be an increasing inconvenience rather than, potentially, life threatening;

SJR: Do you think your patients have any idea what's ahead of them? Are they frightened of the dementia? Do they understand what might be ahead or?

Margaret: Mmmm, sometimes yes. Sometimes they do. Emm, sometimes they feel worried, maybe about getting lost or ehh, like the, sometimes they lose their key, their room key, maybe someone is stealing something like their skirt or.. We had some patient here. All the time she was looking for the key. (RN).

Finally, this focus on functional aspects of care is very common among the participating nurses and was addressed in chapter six, with reference to care and care planning. However, the functional focus of the nurses does limit their overview of the journey and draws their attention away from the final destination or end point of the journey. Indeed, Steven, a nurse who considered his patients to be dying and considered his role to be palliative care, focussed on function;

Steven: I like the patients to maintain as much of their independence, independence and functioning as, whatever we can manage for them. So, that being the case, I would be encouraging the patients to assist as much as they can with their personal care. Em, when they're doing that, rather than just going in and doing everything for them, which might seem to be more easier on the staff em. But certainly if you do the, if you do that, it's not doing them a great deal of help.(MH)

The focus on function has emerged in every area of data collection and seems to be prevalent, regardless of the perceived point of the individual's dementia journey. This will be discussed further in chapter nine.

General uncertainty characterises the end of this dementia journey. Some had not considered it possible to die from dementia and heard this for the first time during the data collection. This demonstrates an interesting gap in education but also highlights the fact that the prevailing culture in the medical and shorter stay mental health work places, is not to think in terms of death or palliation with those who have dementia. The extract below highlights some of the differing views from nurses working in the same clinical area.

SJR: And would you consider then employing kind of palliative approaches to your care?

Joanne: Mmmm, not really (talked over by both Jim & Simon's responses – not heard during the group but clear on tape)

Jim: That's what we do all the time.

Simon: That's all we do, I mean everyone that we've got coming into our ward sort of a) the dementia's usually well established and has been for a while hence the fact we're long term care, ehh I mean 99% of people we get we keep until until they die and they don't move on elsewhere. So, from the minute they walk in door this is the last place they're going to be so, sort of, from the word go it's almost a palliative approach. Because by the time they've got to us the dementia's severe and we're not going change that. We're not going to be doing anything really to the dementia (MH).

The nurses' views of the destination of the dementia journey appeared to be related to the workplace, as the excerpts above demonstrate. The influences of work experience, ward ethos, environment, specific client group, socialisation and education all appear to be significant.

8.5.1 Implications for Care and Care Planning

Understanding dementia as a journey with an uncertain end has implications for care and care planning for this group of patients. While ideas of progression are inherent in the journey metaphor, the lack of insight about where the progression may lead significantly limits the nurses' ability to plan care for the future. Previous chapters have highlighted the nurses' desire to avoid thinking about the distasteful aspects of dementing illness and have presented data which show nurses using the language of disease or confusion in order to avoid thinking about dementia and, particularly, about advancing symptoms of dementia. The data which show nurses conceptualising dementia as a journey, similarly show nurses avoiding consideration of dementia and its progression.

Nursing care incorporates knowledge of physiology and disease, research and evidence and crucial interpersonal skills. Understanding the individual, their social situation, goals and lifestyles are important factors in shaping the care that a nurse gives. In my own practice, I worked with many nurses who gave effective and compassionate care. However, I also worked with nurses who focused heavily on one or other aspect of nursing care. For example, I recall a nurse who cared deeply about the individuality of his patients, offering care which took account of that individual and his/her family but often omitted important details related to the individual's disease, forgetting medication or dietary requirements. Other nurses were efficient in caring for the disease but forgot that a patient lay in the bed with that condition. Those nurses who nursed only what they could see in front of them, were limited by their lack of vision, often failing to consider problems which may lurk around the next corner. The limited view of the end point of a dementia journey highlights similar difficulties.

Nurses who care for people living with dementia but fail to envisage the end of the journey are limited in their caring potential. It may be possible to give compassionate and personal care on a day to day basis or to offer effective technical nursing skills

when necessary. However, without a view of what may be round the next bend in the road, there are significant limitations to the nurses' capacity to adequately prepare the individual for the remainder of the journey. Some nurses did demonstrate awareness of progression but were not aware of the potential extent of that progression or of the potential for death. These nurses could offer patients care which prepared them for progression, as they did incorporate a vision of the future in their own understanding. While these nurses too may be limited in their practice, they could start to prepare their patient and his/her family for the future, including also the patient's own personal wishes.

8.6 Conclusion

In conclusion, this chapter has considered the conceptualisation of dementia as a journey. Definitions of 'journey' were presented and some social context was added to these definitions. The place of the journey metaphor in healthcare literature was discussed. Thereafter, two ways of understanding dementia as a journey were presented. The first, more dominant understanding, was the view of dementia as a journey towards eventual death. This raised important differences between mental health and general nurses, as their understandings and experiences were quite different. Understanding dementia as a journey towards the end of life was also significant in terms of determining approaches to care. Palliative care was discussed in relation to the care given by contributing nurses and also the nurses' understandings of hospital based palliative care. Thereafter, a long term approach to palliative styles of care was discussed and the idea of social palliation was introduced. These ideas were challenging for some contributing nurses who could not reconcile their own experiences of caring for people with dementia and the palliative approaches being highlighted by colleagues from other clinical settings.

Thereafter, the chapter moved on to discuss those nurses who conceptualised dementia as a journey but had no vision for the end point of that journey. Factors

contributing to this anomalous understanding were discussed; for example, varied death certificate reporting, organisation of the inpatient dementia care and the focus on functional aspects of care. Furthermore, the nurses' use of language to avoid the reality of progressing dementia and the positive views of people being 'happy in their own world' demonstrated nurses' avoidance of the potentially distasteful aspects of progressive dementia. Finally, the implications for care and care planning of conceptualising dementia as a 'road to no-where' were discussed and the limitations of nursing care emphasised.

CHAPTER NINE

FACTORS WHICH INFLUENCE CONCEPTUALISATION

9.1 Introduction

This study set out to explore nurses' conceptualisation of dementia and how this conceptualisation relates to nursing care and care planning for those living with dementia. The preceding chapters have presented data showing that, far from having one single common conceptualisation of dementia, nurses understand dementia in four main ways. This chapter discusses factors which have been found to influence the conceptualisation of dementia, considering four main themes emerging from the conceptualisations presented in the previous four chapters. Issues arising from each of the conceptualisations are raised and the ways in which these issues shape and contribute to the nurses' conceptualisations are discussed.

9.2 Four Conceptualisations

Perhaps with the naivety of a novice researcher, I began this research with a view to finding *the* way that nurses conceptualise dementia. I was well aware that individual nurses thought differently about dementia but imagined that, if these thoughts were explored in detail, there would be commonalities underpinning the nurses' understandings which would allow a single way of conceptualising dementia to be uncovered! I soon realised that this thinking was fundamentally flawed! The data demonstrate that nurses do not conceptualise dementia in one specific way but, rather, use a number of different understandings. While most of the contributing nurses each had one way of conceptualising dementia, a number of them used

multiple understandings and did not focus on one conceptualisation to the exclusion of all others. The preceding chapters show how each conceptualisation can shape understanding and influence the nursing care of patients living with dementia. Discussion in each of the data chapters has shown how each conceptualisation fits within the dynamics of the field and can be related to knowledge and practice in the study field. Bourdieu encourages the researcher to set findings within the wider social world, making explicit links between the study field and the dominant fields of power. The study field of 'inpatient dementia care' is closely related to the larger and more powerful field of 'hospital care'. In order to make the links between the study field and the dominant field of power explicit, the discussion in this chapter does not focus specifically on the four conceptualisations which have been presented in preceding chapters but, rather, focuses on four themes which emerge from the nurses' conceptualisations as important influencing factors. These themes underpin the nurses' understandings, providing motivation and influence to nurses in their thinking.

The four themes, which will be examined in more detail in the pages which follow, emerge directly from the nurses' conceptualisations. These themes have been discussed with specific reference to the data earlier in this thesis and are now brought together, in order to clarify the nurses' underlying understandings and factors which shape their conceptualisation of dementia. This chapter begins by considering the inherent differences between mental health nurses, general nurses and their respective workplaces and showing how these factors relate to the conceptualisation of dementia. Thereafter, the chapter moves on to discuss two themes relating to the care of patients who live with dementia, namely, the nurses' focus on function and their use of individualised care. The final theme, defence against distress, explores some factors which were found to motivate nurses in their conceptualisation of dementia.

9.3 Dementia Nursing: Challenging Identity?

Nursing care of individuals living with dementia takes place throughout the National Health Service and employs the skills of nurses from a variety of backgrounds and experiences. This study has focused on inpatient hospital care and has benefited from contributions from mental health nurses and registered general nurses. Dementia has been considered to be a challenge to the identity of the nurses who work in this field (Watson 1997). The organic aetiology of dementing illness sets it apart from many other diseases which fall under the care of mental health services. However, the effects of dementia on personality, behaviour, mood and interaction mean that individuals, living with dementia, may not find that care from general nurses in busy medical or surgical wards adequately meets their needs. In many cases, the care needed for concomitant health problems determines the location of care. For example, many older people with dementia can be found in orthopaedic areas after falls or in respiratory wards with chronic lung diseases. These individuals are cared for by nurses who work in specialist medical or surgical settings. Some older people are admitted to hospital because of difficulties directly related to dementia. For example, people may develop infections which exacerbate the chronic features of dementia or may be admitted when the domestic situation breaks down. These individuals are likely to be admitted to general medical or care of the elderly units and undergo assessment. A final group of patients, those who develop features of dementia which can not be managed either in the home or by general nurses, are commonly admitted to mental health services. These statements make generalisations about a complex service profile and it is not uncommon for alternative referrals to be made. However, these general trends were reflected in the research settings identified in the study field.

Throughout the four data chapters, it has been clear that, while contributing nurses from all backgrounds conceptualised dementia in each of the four ways presented, mental health and general nurses often came to their understandings from different standpoints. The nurses had different ideas about dementia as a disease, with mental health nurses attending more carefully to the specific diagnostic labels, while general

colleagues focused on the umbrella term. The level of detail in their knowledge could also be contrasted and different features of dementia were noted in observation by nurses from different backgrounds. Mental health nurses viewed confusion as a feature of a much greater clinical syndrome, while a number of general nurses considered the meaning of dementia to be encapsulated in the term 'confusion'. Both sets of nurses recognised dementia as a journey and conceptualised it in that way. However, their visions of the 'destination' were contrasting and most of the contributing nurses could only envisage the start or the end of the journey, rarely both.

The contrasts raise important questions which can be addressed with reference to Bourdieu's Theory of Practice. The capital exchanged in mental health settings differs from that exchanged in general settings. Different observations and knowledge are influential and the dominant paradigm of psychiatry wields different power and influence from its medical counterpart. For example, restraint, locked doors and powers of detention all shape the organisation and practice of psychiatry in a manner not understood in medical and surgical settings. Cultures also differ, with different levels of noise, modes of address and expectations. For example, during observation in a mental health setting, I watched a patient crawl around the room, under chairs and between patients' legs. I immediately felt agitated, looking round for a reaction from staff. There was no reaction and a number of nurses and visitors even said 'hello' to the man as he crawled up the corridor. In my own nursing practice within a medical ward, this type of behaviour would have been both hugely unusual and unacceptable. Unusual behaviour of this magnitude would rock the established social norms in a general setting. Neither nurses nor visitors would accept the sight of a patient crawling in the ward and nurses would be considered neglectful in their care if they allowed a patient to behave in this manner. This example demonstrates the differences in expectations and habitus between the two clinical settings and reflects something of the paradigmatic differences between medicine and psychiatry. The field of inpatient dementia care is characterised by these differences and the boundaries of that field are challenged by differences in power

dynamics and types of social capital as well as differences in habitus which are demonstrated by the example given above.

The significant differences between the two settings extend to the recruitment and education of nurses. Care and compassion are central to nursing in both mental health and general areas. However, few of the nurses contributing to this study were dual trained and those who were felt more comfortable in one setting than the other, suggesting that individuals may be more suited to specific types of nursing. Education of nurses also reflects the differences in approach, with student nurses completing a common foundation programme before pursuing pre-registration education in either mental health or general adult nursing.

In each of the four conceptualisations of dementia presented in the preceding chapters, mental health nurses and general nurses came to the same conceptualisations through different ways of thinking. The differences in knowledge base, habitus and education outlined above go some way to explaining this phenomenon and may account for some of the emphases which nurses placed on specific aspects of their conceptualisation. However, the sample for this study, outlined in chapter four, included more general nurses from short stay and assessment wards and more mental health nurses from long stay and continuing care wards. This anomaly may have influenced the data collected and the impressions gained through observation. Medical continuing care wards were not included in the study as they were found to have few patients with dementia. Those who did have dementia also suffered significant physical ill health which was the primary focus of their care. In mental health, the assessment wards also had few people with dementia. The main contact between mental health nurses and those in the early stages of dementia was through the community psychiatric nursing (CPN) service. These nurses were not included due to the study's focus on the inpatient sector. The omission of these groups of nurses from the study may have influenced the views that nurses had of the extreme ends of the dementia journey and may have

contributed to the distinct lack of understanding of both ends of the spectrum by any of the contributing nurses.

For example, mental health nurses focused on the end stages of dementia, considering palliative aspects of care and reflecting on lives being eroded by dementing illness. General nurses had more experience of early stage features of dementia and discussed practical aspects of care with little regard for the potential progression. The sample utilised in this study may have influenced the data but the focus groups and interviews did probe the understandings of nurses in an attempt to reach some of the understandings, developed from nursing experience, but discussed in a more abstract manner by nurses. The data reflect nurses' understandings of dementia from their work experience while also drawing on personal experience, theoretical knowledge and lay sources. The polarised views of dementia progression, described most significantly in terms of the conceptualisation of dementia as a journey, may have been influenced by the sample in this study but also demonstrate the other significant educational and paradigmatic differences between mental health and general nurses, outlined earlier in this chapter. The limited overview of dementia which the nurses demonstrated is an important finding which has huge implications for practice and education and is discussed further in chapter ten.

The nurses in this study conceptualised dementia in four different ways. Far from having one single 'nursing' conceptualisation, they chose to use each of the four conceptualisations, sometimes in combination, to explain their understanding of dementia. Mental health and general nurses placed different emphases on elements of the conceptualisations, focusing on aspects of disease and confusion in different ways and demonstrating contrasting understandings of the 'journey' of dementia, with little common overview. The significant differences between mental health and general nurses were an important theme in this study and reflect the challenge which dementia poses to the identity of both sets of nurses. Structural aspects of the field, dominant paradigms and differences in education and habitus are considered

influential factors in explaining these differences. The sample of nurses in this study may have made these differences more evident, although the style of questioning use during data collection sought to take in nurses' views of dementia as an abstract concept, as well as through reflection on practice. The limited overview of dementia, which both mental health and general nurses demonstrated, has significant implications for both practice and education which will be discussed in chapter ten.

This chapter now moves on to consider two key themes about care which emerge from the conceptualisations of dementia presented earlier in this thesis. The focus on function and the pursuit of individualised care are thought to influence nurses' conceptualisation of dementia and will be discussed in the pages which follow.

9.4 Focus on Function

The nurses' focus on function in their discussion of dementia and the care of people living with dementia was something which I took for granted during data collection and much of the analysis. As a nurse, my own understanding of the language of function let the significance of the focus go unnoticed. Only when reflecting on the data after a maternity break, did the significance and dominance of the nurses' focus become clear. Regardless of whether nurses conceptualised dementia in terms of disease, confusion, memory or as a journey, the nurses used function in order to illustrate their conceptual understandings and describe the organisation of their care. Function was, therefore, an influential factor in shaping nurses' understandings and contributing to the very individual process of conceptualising dementia.

Those who conceptualised dementia as disease understood functional deficits to be symptoms or features of that disease. They expected functional decline and gauged the severity of disease in terms of functional deficits. This approach often proved to be useful in terms of organising support for individuals on discharge and organising

workload in the ward area, where functional deficits had to be met by nursing input. Nurses organised staffing and described their workload in terms of their patients' functional capabilities. For example, extra staff could be ordered when ward staff were caring for more heavily dependent patients and those who needed help to wash, dress or feed were spread between nursing teams rather than being the responsibility of a single nurse or team.

The dominance of function as an organisational tool in the inpatient setting was clear in each of the clinical settings visited in the course of data collection. Furthermore, dominant paradigms such as risk, which pervade all aspects of modern day nursing care, also emphasised the focus on function. Documentation recorded individual functional abilities in order to ascertain what kind of care should be provided and by whom. Assessments of function were required before moving or bathing a patient and the parameters of care were similarly determined by functional assessment. The focus on function, therefore, is part of the very fabric of the field and has become one of the 'taken for granted' structures on which the field of inpatient dementia care is based. This is reflective of the wider social world in which litigation has become an important part of peoples' lives and clearly shows the link between the field of inpatient dementia care, the wider field of the hospital and the social world within which these social systems operate.

In many cases, individuals were admitted to hospital because of declining functional abilities. Individuals were often unable to manage at home and were admitted to hospital after falls or in the throws of an infection which threatened their ability to function independently. Nurses used their preferred way of conceptualising dementia to explain the functional deficits and, in turn, these explanations reinforced individual nurse's responses to dementia and their conceptualisation of dementing illness as a whole. Disease, confusion and memory were all understood to underpin individuals' functional deficits - understandings which subsequently shaped the nurses' overall views of dementia.

The dominance of function in terms of structural aspects of the field is overwhelming. In light of the nurses' understanding of functional deficits as symptoms or features of dementia, their focus on function in the assessment and care of patients seems like an obvious next step. Whether conceptualising dementia as disease or in terms of confusion or memory, function remained central to the different understandings, as well as being an important determinant of organisation and, subsequently, of the nurses' care.

The focus on function was equally apparent in data from both mental health and general nurses and was translated into care strategies in a number of different ways. Once again, the focus on individual functions detracted from an overall view of dementia and encouraged nurses to consider specific aspects of an individual's care at the expense of the overall experience. Assessment of an individual's ability to wash, dress or walk independently took scant account of the experience of dependency, insecurity or an individual's fear for the future. While some of these experiences and concerns were tackled by nurses at other times, the organisation of care often promoted a focus on function, at the expense of the aspects of individual patient support which may have emerged in a less functionally focused interaction. The nurses' focus on function, therefore, was significant in undermining the overall view of dementia. This will be discussed further in chapter ten.

The approaches to care adopted by the nurse were found to be determined by their conceptualisations of dementia and the organisation of the wards. For example, some nurses attempted to promote independence by reducing their own input and allowing the patient more functional autonomy. In some cases this was a strategy which reflected the rehabilitation focus of the care setting. Furthermore, this approach often took little account of the cognitive declines apparent in dementia, and the limitations of nurses' knowledge of the likely impairments associated with dementia became apparent. In other examples, memory aids were used to improve function when nurses conceptualised dementia in terms of memory. Some nurses, who

conceptualised dementia as a journey, chose to centre care around the promotion of personal autonomy and decision making, allowing individuals to express their wishes and make personal choice while being supported functionally wherever necessary. These interactions were mainly observed in continuing care environments where individuals were, typically, less able to function unsupported and nurses were keen to consider palliative approaches in care.

The nurses' focus on function was a dominant theme and emerged from data on each of the four conceptualisations of dementia presented earlier in this thesis. The structures of the care settings, organisational factors and dominant paradigms such as risk, all contributed to the nurses' focus on function. Those who understood dementia as a disease also understood functional decline to be a symptom or feature of that disease. In those cases, the consideration of an individual's functional ability was an obvious manifestation of this conceptualisation. However, this focus on function also influenced the process of conceptualisation itself with nurses observing functional decline and subsequently making sense of this observation by using the model of disease which was part of the dominant understanding and habitus of the field. The focus on function undermined the nurses' ability to have an overview of dementia. Nurses were tacitly encouraged to focus on individual functions and capabilities at the expense of a more holistic view of the individual living with dementia. The nurses' conceptualisation of dementia was strongly related to the way in which they focused on function in their care. Individual nurses, understanding dementia in specific ways, were observed operationalizing their understanding in the way in which they cared for patients. This was true of nurses in both mental health and general settings who were seen to support their patients' functional abilities using a variety of supportive strategies.

In the following section, the nurses' conceptualisation of dementia will be discussed in relation to the use of individual patient care.

9.5 Individualised Care

The literature on dementia care, outlined in chapter two, discusses caring for people individually using person-centred approaches to care. Relationship and family-centred care strategies (Nolan et al. 2002), which have emerged following the dominance of person-centred care, are based on the same assumptions about individuality and the importance of reinforcing the sense of self in the face of advancing dementia. While these strategies go further, suggesting the inclusion of carers and family members in the care process, the focus on individuality remains constant. Nursing literature also reflects this focus, with nurses being encouraged to think about patients individually, taking in aspects of biography, autonomy and personal experiences of ill health, rather than simply treating the disease process. This section has been entitled ‘individualised care’, as this is the terminology which was used by nurses in this study. Very few of the contributing nurses used any other terminology. This was somewhat surprising as the influence of the literature was not evident. However, the overall themes of the nursing and dementia literatures were understood by nurses and formed the backdrop to their promotion of individualised care practices.

As noted in the introductory pages of this chapter, I started this study expecting to find a single nursing conceptualisation of dementia. After the first two focus groups, it became immediately obvious that this was not to be the case. Individualised care, as described and promoted by the nurses, was the first reason to question my initial belief. The nurses were clear in their thinking that dementia could not be understood in one particular way because each individual presents so differently. This startling revelation raised questions about the study itself and about my facilitation of the focus groups. I worried that the simplistic questions posed in the focus groups were not allowing the nurses to develop depth in their thinking and were not helping the nurses to consider any more than their day to day experiences in the clinical areas. Only through analysis of the data and time spent immersed in clinical areas during observation, did it become clear that ‘individualised care’ was being used, by nurses, as a phrase to promote two specific images of their care.

Firstly, the nurses understood care which focused on the individual and their family to be 'good practice'. That is to say, they understood that high quality nursing care should be individually tailored to the needs of the patient and best practice in dementia care similarly focuses on the person and the reinforcement of individuality, using a variety of well documented strategies. The nurses, therefore, promoted a positive view of themselves and their practice through the language of 'individualised care'. Secondly, the wide variation in presentations of dementing illness does require nurses to take account of individual needs and fluctuations in condition. This was something which was clear to me in developing the strategies for informed consent for this study, outlined in chapter four. Many nurses did provide care which was truly individual in its nature. Individual capabilities were recognised, likes and dislikes understood and significant relationships and roles respected. In these cases, nurses used their own conceptualisation of dementia to shape their approach to care, while ensuring that the individual was always central to the care given. Finally, some nurses concealed gaps in their knowledge about the course of dementing illness or specific therapeutic approaches by using the rhetoric of 'individualised care' to cover their lack of overview in relation to dementia. These approaches were identified in the contributions of nurses who conceptualised dementia in a number of different ways.

For example, many of those who conceptualised dementia as disease had limited knowledge of the specific diagnoses associated with the range of dementing illnesses. Their responses often included assertions that these specific diagnoses had limited utility, as each patient had to be treated individually. Furthermore, nurses who considered confusion or memory to be central to their understanding of dementia, remarked that other emerging features of dementia were considered in the course of individual assessment. Therefore, swallowing or continence issues were understood and taken account of at an individual level but were never attributed to the dementia. This strategy on the part of nurses contributed to their limited overview of dementia and prevented nurses from understanding the wide range of factors which may emerge throughout the course of dementing illness.

The preoccupation with the care of the individual was a dominant theme throughout the study and could be described as a factor which has influenced nurses in the formation of their conceptualisation of dementia. Individualised care has, in turn, been influenced by nurses' varying understandings of dementia and has been manipulated by nurses to back up their individually formed views of dementia. Nurses who conceptualised dementia in each of the four ways described in this thesis recognised individualised care as a positive approach to the care of people living with dementia. For some nurses, it was a strategy which facilitated the use of a conceptualisation of dementia which did not take account of all the features displayed by the patient. For some, it was a positive approach to care which took account of individual fluctuations in condition and helped individuals to plan for their future. A few nurses used the language of individuality as currency to assert their own position within the field, manipulating language as capital when knowledge was lacking.

9.6 Conceptualising Dementia as a Means of Protection

The final theme discussed in this chapter is the complex process whereby nurses conceptualised dementia in order to protect themselves from the perceived horror of the concept. This process became evident in each of the four conceptualisations presented in this thesis and demonstrates the underlying and unspoken fear associated with dementia. My own personal account, given in chapter two, makes fleeting reference to the fear which prevails in families where dementia is prevalent. However, fear is not one of my over-riding emotions when considering dementia. With little, if anything, that can be done to protect oneself from dementia, it seems, to me, that dementia must surely be left to fate. I do not waste time thinking about the likelihood of myself or one of my family developing dementia in the future. However, this strategy reflects the avoidance tactics which emerge from the nurses' conceptualisations. Conceptualising dementia as disease allows nurses to put distance between themselves and the diagnosis, setting dementia apart from normal ageing and leading to the conclusion that dementia is not an inevitable consequence

of ageing. Conceptualising dementia in terms of confusion means that the word 'dementia' need never be uttered. The full magnitude of the diagnosis need never be recognised and some minor muddles could be seen to constitute dementing illness. Similarly, an understanding of dementia which focuses on memory, can lead to images of forgotten keys and shopping lists. Applying the language of memory to other organs can even reduce the horror of choking and eventual death, focusing instead on people forgetting to swallow and hearts forgetting to beat. Even those who conceptualise dementia as a journey allude to people being happy in their own world.

Throughout this study, nurses have demonstrated their considerable skill in manipulating their conceptualisation in order to protect themselves from the tacitly acknowledged horror of dementia. Stigma, dribbling, decline and death were discussed by nurses and many were aware of these aspects of dementia. However, many more manipulated language in order to cover these distasteful aspects. Knowledge was recognised to be limited in many contributors and there may have been a number of nurses who were unaware of the extent and scope of dementing illness. Indeed some nurses openly admitted their lack of detailed knowledge and spoke about where they might find out more information if necessary. Perhaps it is noteworthy that, despite being aware of potential information sources, these nurses had not sought more detailed information about dementia. Each of the nurses' conceptualisations shows their ability to avoid facing some of the unpleasant aspects of dementia. This complex process of avoidance, a skill honed by the nurses, reflects the wider social world and the importance of autonomy, competence and cognitive abilities in the world in which we live.

9.7 Conclusion

This chapter has discussed some of the findings from this research, considering some of the factors which influence nurses' conceptualisations in more detail. The four conceptualisations of dementia, presented in the preceding chapters, represent the

nurses' understandings of dementia. These understandings, both singularly and in combination, are used by nurses in order to make sense of the complexity of dementia. This chapter has focused on four themes which have emerged from the nurses' conceptualisations; namely the differences between mental health and general nurses in dementia care, focus on function, individualised care and, finally, the use of conceptualisation as a means of protecting nurses. These four themes allow the conceptualisations to be discussed in more detail and understood more fully. Each of these four themes influences nurses in their conceptualisation of dementia and form part of the nurses' individual understandings. This chapter has demonstrated how these factors can contribute to the conceptualisation process as well as how they are then manipulated by nurses in order to demonstrate specific modes of understanding dementia.

The differences between mental health and general nurses' approaches to dementia care and structural differences between their workplaces were discussed in relation to the wider field and power dynamics of hospital care. Bourdieu's theory of Practice allowed these structures, cultures and organisational paradigms to be brought together. Dementia challenges the identity of both sets of nurses and allows structures and dominant paradigms to be questioned. Nurses from different backgrounds placed different emphases on aspects of the four conceptualisations presented in this thesis. These differences were noted and the polarisation of views about the scope and extent of dementia were highlighted. The place of the research sample in exacerbating this polarisation was considered.

Thereafter, sections on nursing care introduced the focus on function and the notion of individualised care. Both of these themes were dominant aspects of all four conceptualisations. Bourdieu's writing, once again, allowed these findings to be discussed in relation to the social world and their influence on conceptualisation to be noted. While structural aspects of the field encouraged nurses to focus on function, this reflects the wider social world where increased litigation and the

‘blame culture’ necessitate the repeated assessment and documentation of function. This focus also limited any holistic view of an individual’s life with dementia by fragmenting the view and reducing the individual to a list of capabilities. Similarly, individualised care also allowed nurses to ignore the process of dementia as a whole and consider individual features as they affected the patient themselves. Rhetoric and the place of capital within the study field were also considered in the discussion of individualised care as a determinant of good practice.

Finally, this chapter discussed the nurses’ conceptualisations as means of protecting nurses from the enormity and potential horror of dementia. The influence of the wider social world, stigma and distaste were considered. In addition, the limited knowledge of dementia, displayed by some contributing nurses, was highlighted as a factor which may curtail nurses’ overall view of dementia. These factors are highlighted again in the discussion in chapter ten.

The final chapter of this thesis offers a discussion of findings and outlines the implications of this study for both practice and education. Thereafter, the unique contribution of this study is highlighted before suggestions for future research and some concluding remarks.

CHAPTER TEN

DISCUSSION, REFLECTIONS AND CONCLUSIONS

10.1 Introduction

This chapter brings together the material presented earlier in this thesis and discusses the relationship between nurses' conceptualisation of dementia and their care of older people who live with dementing illness. The key findings of this research are summarised and aspects of these findings and their relationship with nursing practice are discussed in some detail. Implications of these findings for practice, research and education are outlined. Reflections on the findings, research approach and the next steps are offered in line with Bourdieu's reflexive sociological approach to research. Finally, concluding remarks bring the chapter and the thesis to a close.

10.2 Summary of Findings

This study was developed in response to questions emerging in nursing practice and particularly from my own work with Sally and her family, introduced in chapter one. The study involved nurses from a variety of clinical settings in an attempt to gain an overview of nurses' conceptualisation of dementia and then to relate this conceptualisation to nursing practice. The following summary outlines briefly the key findings of this work before a more fulsome discussion of the ways in which these findings relate to nursing practice.

Nurses explored their understandings of dementia and dementia care in focus groups and interviews, generating ideas and explaining their views and opinions on dementia and the nursing care of dementia patients. Observations of these nurses in their work with people who live with dementia further informed this study. Nurses were found to conceptualise dementia in four main ways. These conceptualisations were used individually by many nurses but some combined more than one conceptualisation in order to reach their own specific understanding of dementia. The four conceptualisations, presented in chapters five to eight, were as follows;

- Dementia as a disease
- Dementia as a memory problem
- Dementia as confusion
- Dementia as a journey

The medical model, which provides the backdrop to health care generally, makes the understanding of dementia as a disease a predictable conceptualisation. This approach pervades much of healthcare and is a method of understanding with which nurses are familiar. While nurses felt comfortable conceptualising dementia as disease, their conceptualisation was limited by lack of knowledge about the scope of dementing illness and the specific diagnostic labels. Nurses were found to conceptualise dementia as disease by focusing on the umbrella term ‘dementia’ and using the language of disease to portray understanding. Problems of diagnosis and limited treatment options further limited the nurses’ conceptualisation and contributed to limited discussion of progression between nurses and their patients.

As a dominant feature of dementing illness, memory problems were part of the nurses’ assumed understanding of dementia. Nurses used memory to construct understanding in two main ways. Firstly, they used memory to conceptualise dementia in its entirety. These nurses considered all aspects of dementia to relate to

memory, from the initial and most obvious features, to the physical declines of end stage dementia. As a result, some nurses used extreme examples to illustrate this conceptualisation and data which suggest that hearts ‘forget’ to beat were presented. Secondly, nurses understood memory problems to be one feature, amongst many, of dementia. This fragmented vision of dementia, once again, reduced the nurses’ ability to develop a holistic view of dementia and dementia care.

Confusion was a term used often by nurses in relation to individuals who live with dementia. Some found difficulty in determining the differences between acute confusion and dementia, while others considered the terms synonymous. This conceptualisation of dementia, as confusion, limited the nurses in their care and care planning as the variety of other features of dementing illness could not be attributed to a diagnosis of confusion. However, some nurses chose to construct understanding of dementia in this way in order to avoid the full significance of diagnosis and to distance themselves from the perceived horror of dementia. A number of nurses rejected the conceptualisation of dementia as confusion on the grounds that the finality of dementia set the two concepts apart. Finally, the phrase ‘pleasantly confused’ was discussed in detail and the nurses’ use of this phrase to distance themselves from negative aspects of dementia was explored.

The final conceptualisation of dementia as a journey was presented in chapter eight. This much used metaphor was considered specifically in terms of the ‘destination’ of the journey. Data reflect the use of the language of journey by many nurses. However, the destination of the dementia journey was unclear, with some nurses considering dementia to be a final journey while others had no vision of the journey’s end. This dichotomy raised important questions about care of people who live with dementia. Palliative care of people with dementia was considered and, once again, the nurses’ uncertain overview of dementia was highlighted.

Each of these conceptualisations was discussed in detail and related to the structures of the study field and the care practices of the nurses. The discussion in chapter nine focused on four themes which emerged from the nurses' conceptualisations and discussion of care practices. These themes explored the nurses' understandings more fully, suggesting motivations and challenges inherent in the conceptualisations presented in this thesis and demonstrating factors which influenced the nurses in the process of conceptualisation. The following section discusses the nurses' conceptualisations and highlights the ways in which these conceptualisations and the factors which influences them can be related to nursing practice.

10.3 Discussion

The link between practice and theory has been a defining feature of this study from its inception and as such, it is fitting that discussion in this final chapter focuses on the relationship between the theoretical findings of this work and the practice of nursing older people who live with dementia. The research questions which this work has addressed were developed from practice and were a real 'burning issue' for me as a practising nurse. As outlined previously, I expected to speak to a range of nurses and find underneath a sea of different responses, a common 'nursing' understanding of dementia. However, this was not the reality of this study. Nurses were not found to conceptualise dementia in one way but rather to use four different ways of explaining dementing illness. Some of these conceptualisations were used singularly while others were used in combination which was another surprise. What was clear, however, was that each of these four ways of conceptualising dementia brought both benefits and limitations for nursing care of older people.

10.3.1 Conceptualising Dementia

Conceptualising dementia as a disease was a popular way of thinking, supported by the dominance of the medical model in the study field. The use of a disease label served to depersonalise dementia, creating distance between the nurse and the label

and also allowing the disease to take the blame for distasteful features of dementia or behaviours demonstrated by patients. This conceptualisation allowed nurses to feel comfortable to dementia as a condition like any other with treatments, symptoms and objectively recognisable features. However, the limited treatment options and the lack of potential cure posed a challenge to nurses who considered dementia in this way. Furthermore, the symptoms or features of dementia were less easily objectified than symptoms of many other conditions with personality changes, mood swings, confusion and word finding problems being more difficult to rationalise than recognisable physical features of other conditions.

Confusion provided nurses with a way conceptualising dementia which did not require them to use the life changing and potentially stigmatising term 'dementia'. However, this conceptualisation too had limitations with difficulties in visualising the extent of impairment which is possible with dementia in the face of the rather trivial and common-place word 'confusion'. In some cases nurses were happy to limit their view of dementia to that of simple confusion and this proved to be an interesting feature of data in this area.

Memory problems are perhaps the most common and best known feature of dementia and formed an important part of nurses' conceptualisation of dementia as a whole. Many nurses used memory to explain features that they saw in their patients and to understand many aspects of dementia. In some cases this was taken to extremes which demonstrated alarming gaps in knowledge with nurses talking about hearts forgetting to beat and patients forgetting to swallow. At one level 'forgetting' proved to be a useful way of characterising what was happening to patients and allowed nurses to link physical body functions with those of the mind. However, the limits of this conceptualisation were underlined by the gaps in knowledge which allowed nurses to truly believe that patients' hearts could 'forget' to beat.

The final conceptualisation presented was that of dementia as a journey. This metaphor is arguably overused in health care. However, in this case, the ‘destination’ of the journey was largely unknown and the idea of a journey having a beginning, middle and end was problematic. This difficulty raised a significant problem which was a feature of data in each conceptualisation, that of lack of overview. The inability of nurses to visualise the beginning, middle and end of dementia was both alarming and unexpected. It also raised significant issues regarding the care of older people which will be discussed in the following section.

10.3.2 Lack of Overview

In discussing the findings of this research, the nurses’ lack of overview of dementia is one of the most striking factors and is, potentially, one which limits practice significantly. As discussed in chapter nine, there are some sample related reasons why nurses may not have demonstrated awareness of both the early and end stages of dementia. Many mental health nurses who care for those with early stage dementia work in the community and were omitted from this study while many general nurses care for people with complex physical needs near the end of life rather than those with end stage dementia and they too were, therefore, omitted from the study. However, none of the contributing nurses could visualise the early stages of dementia, understand how their patients might live independently with dementia and also understand how things might change over time as the limitations of dementing illness increase and the end stages of disease draw closer. Indeed the majority of nurses included in this study could understand clearly only part of the dementia spectrum. For some this was an acute awareness of the end stages, views about assisted feeding, inability to swallow or move, palliative approaches to care and eventual death. For other nurses, the focus was wandering, practical difficulties at home, diminishing ability to cook or plan meals, shop or drive. These polarised views were irreconcilable. These views prevent nurses from providing care which takes account of both the individual’s abilities now and their future potential. They also restrict the ability of the nurse to imagine where the person has come from, what has happened to them over the course of the dementing process and how that relates

to the individual now requiring end stage care. The limitations of the nurses' lack of overview of dementia is staggering and has huge implications for nursing care.

The lack of overview is partially related to the groups of patients of whom the individual nurses have experience. Differences between mental health nurses and general nurses in this regard were outlined in chapter nine. However, other factors influencing the nurses' conceptualisation also relate to this significant lack of vision. For example, the focus on function and dominance of theories of individualised care, which were outlined in detail in chapter nine, both contribute significantly to the lack of overview of dementia. Seeing each patient as an individual and tailoring care towards that individual and what he/she is able to do were strategies which nurses considered to be positive, fulfilling the requirements of individualised or person-centred care planning. However, the nurses failed to realise that by limiting their view to individual elements of function, they were ignoring the bigger picture of dementing illness and limiting their care to the patient's current position with no view for what may lie ahead. This strategy encourages nurses to nurse 'what they see' with little consideration of how the current position fits with both past and future. This must surely limit the capacity of the nurse to prepare the patient and his/her family for what might be ahead, to encourage planning ahead for a time where decision making capacity may be compromised or simply encouraging patients to make the most of time before the expected declines which may lie ahead.

In reflecting on these findings I find myself annoyed by the nurses' lack of vision and perturbed by the way in which positive strategies, designed to facilitate the provision of quality care, could be used to diminish nursing care to the very limited provision which was described by many contributing nurses. There is no doubt in my mind that the nurses did not explicitly intend to limit their care but have employed strategies which have led them to do this unwittingly. The startling lack of knowledge demonstrated by some nurses, paired with the limitations imposed by the

lack of overview of dementia result in care which is significantly limited in its quality.

10.3.3 Defence against Dementia?

The lack of overview and its potential to limit nursing care of those living with dementia is hugely significant. As outlined above, the nurses did not demonstrate awareness of their limiting care in this way. However, throughout this project it has been clear that nurses manipulate their conceptualisation of dementia in order to suit a variety of circumstances. Some of the nurses did not use only one conceptualisation but combined their conceptualisations to pick what they wanted from more than one approach. This was not anticipated in the early days of the research, however, it became clear that not all nurses had a single vision of dementia and many lacked a cohesive conceptualisation. Some of the nurses chose to incorporate understandings from each of the four conceptualisations, bringing them together as necessary to illustrate points about their care or to shape their nursing practice.

Some strategies were employed by nurses in order to distance themselves from the unspoken fear of dementia. For example, the use of a disease label provided the nurses with distance from the potential horrors of dementing illness and also from some of the distasteful elements of the care of such patients. By using a disease label, some nurses were able to think of the mood swings or angry outbursts as part of the disease rather than as personal attacks by an individual patient. Confusion was used in a similar way by some nurses, limiting the possibility of attributing a range of other symptoms to the condition by using the term 'confusion' in place of the more complex and distasteful 'dementia'. The lack of overview of dementia which limits practice so significantly may, therefore, be grounded in an implicit attempt by nurses to protect themselves from the extent of dementia by limiting their own view. Nurses demonstrated limited understanding of the extreme ends of the dementia spectrum, focusing instead on individual features and functional elements. This limited nurses'

conceptualisations to journeys with no beginning or end and immediate care priorities with no view towards the future. These limited conceptualisations may have been manipulated, largely unknowingly, by nurses attempting to protect themselves from the enormity of dementia.

In reflecting on these findings I must also note the large knowledge gaps that I encountered during data collection and analysis. These gaps too prevent many of the nurses from enjoying a useful overview of dementia. This lack of knowledge must be addressed in order to improve care in the future. My own analysis points to the nurses manipulating their conceptualisations of dementia in order to provide a defence against the stigma and potential horror of dementia. However, an alternative explanation may be that the nurses simply do not know any better and the knowledge gaps alone undermine their ability to provide cohesive lifelong care for older people with dementia. While I believe that I have presented data in support of my first line of argument, it could be asserted that I would prefer not to think of nurses as simply poorly informed with alarmingly limited knowledge. As a nurse myself, it may be more palatable to imagine that nurses are frightened by the prospect of dementia rather than that they lack knowledge in this area. Whatever the reason, the lack of overview and the nurses' desire to distance themselves from the global impairment of dementia must be addressed in practice, education and in future research in order to ensure the improvement of patient care. The following sections address the implications of this study's findings for practice, education and future research.

10.4 Implications for Nursing Practice

The nurses were consistently found to have a limited overview of dementia. This has important implications for care, as such limited vision of the beginning, middle and end points of dementia must restrict nurses in their support of dementia patients. Planning for the future is an important aspect of quality care which is limited by the nurses' understanding of dementia.

The focus on function similarly restricts nurses in the holistic care of patients. While a focus on individual abilities may allow care needs to be addressed, it restricts the nurses' ability to give holistic care. The nurses' focus on function is structurally reinforced and changes to this focus must take account of the wider influences on nursing care practices.

Lack of basic knowledge about dementia undermines the quality of care that can be given by nurses. While this study has not focused on assessing nurses' knowledge, the gaps which have become evident have restricted their care and contributed to their construction of understandings of dementia.

Stigma, fear and avoidance of discussions about dementia have contributed to the ways in which nurses manipulate their conceptualisations of dementia. The facilitation of more open discussion of dementia between nurses in a clinical setting, would contribute to the gradual improvement of this significant and deeply ingrained problem.

10.5 Implications for Education

The lack of basic knowledge, displayed by nurses contributing to this study, has major implications for nurse education. Differences between mental health and general nurses need to be examined further in this regard. Furthermore, while changes to education could improve this in future, the updating of the knowledge of those nurses already in practice should be considered.

Both mental health and general nurses had difficulty in recognising features of dementia from outwith their usual field of practice. That is to say, general nurses had little vision of end stage dementia and many mental health nurses could not envisage

the early stages. This significantly reduced the nurses' ability to understand the overview of dementia. Pre-registration nurse education should address this issue through practice placements and theoretical knowledge, prior to qualification.

Finally, more education about specific approaches to care which can be beneficial for those with dementia should be considered. This should include planning for the future, person-centred care, carer support, palliative and end of life care.

10.6 Contribution to Knowledge

This thesis contributes to knowledge in a number of ways. Firstly, it explores a previously unexamined subject area and contributes to greater understanding of the ways in which nurses conceptualise dementia. This understanding has important implications for practice and education, as outlined above. Secondly, this work demonstrates significant differences in understandings between nurses in mental health and general nursing settings. These are significant because of their influence on care practices and in the significant limitations that result from the poor overview that nurses have of the scope of dementia and the range of nursing care required. Finally, this study uses Pierre Bourdieu's Theory of Practice as a research framework, demonstrating how the use of this theory can help with interrogation of the data, analysis of the social setting and subsequent development of theoretical understandings in nursing research.

10.7 Future Research

This study has explored nurses' conceptualisations of dementia and has shown the range of understandings which nurses bring to their care of people who live with dementia. Exploration of the ways in which dementia is conceptualised by those older people who live with it may allow nursing practice to develop in direct response to the needs of older people. This would be an interesting research

development. Furthermore, during the observation phase of this study, it became clear that support workers and auxiliary care staff contribute greatly to the care of patients and the ambience of the clinical setting. As in the case of their registered nursing colleagues, these unregistered nurses' conceptualisations of dementia may also influence their care and would be a worthy focus of further research work. Finally, understanding the views of members of the general public and of those family members, friends and neighbours who care for individuals with dementia, would greatly advance the understanding of dementia within the wider social world.

The findings of this study highlight the inherent differences in understandings, education and experience enjoyed by nurses from mental health and general nursing backgrounds. Older people with dementia are cared for in a variety of care settings by registered nurses from both mental health and general backgrounds. Research which focuses, specifically, on exploring the differences and overlaps in understandings and care practices, has the potential to bring together aspects of 'best practice', and thus improve the nursing care of people who live with dementia.

10.8 Reflections on the Study Findings

The aim of exploring *the* nursing conceptualisation of dementia was quickly overtaken by the drive to understand the multitude of ways in which nurses conceptualise dementia. The four conceptualisations, presented in chapters five to eight, reflect the views of nurses' and incorporate data from a wide range of contributing nurses. Each of the ways of understanding dementia can be related to practice and this, for me, has helped to keep this study 'real' despite its theoretical findings.

This discussion has tackled four themes which emerged from the data and proved to be dominant features of each conceptualisation. The differences between mental

health and general nurses became obvious early in the study and made me question whether the study field of 'inpatient dementia care' could really be considered a single field. Through analysis and re-analysis of the study field (diagram one) it became clear to me that many of the structures and parameters of the field were common to both mental health and general settings. For example, the nurse-patient relationship, the pathology of dementing illness, the influence of the field of 'hospital care' and the wider social world were all common to both settings. However, the paradigmatic differences, contrasting education, different types of individuals taking up roles in each setting and diverse habitus all contribute to important contrasts between the mental health and general areas. These contrasts were obvious to me during observation and I found myself spending considerably longer observing mental health wards, in order to reach an understanding of the unfamiliar environment. This is an area which I hope to explore further in future work.

The nurses' focus on function was nearly overlooked as it was a 'taken for granted' part of my own nursing practice. However, I was shocked, at times, that nurses did not seem able to connect continence problems, swallowing or word finding difficulties with the diagnosis of dementia detailed on a patient's chart. Repeated examples of this made me reconsider the data and I soon realised that the nurses' infatuation with 'how' patients did things contributed greatly to their inability to see the whole picture of life with dementia. Similarly, nurses' repeatedly told me that they assessed patients individually in order to ensure that their care met the needs of the individual. While this sounded good, it also meant that nurses did not need to connect together the symptoms, they could legitimately look after each symptom in an unconnected fashion by using the 'individualised care' rhetoric. Throughout my own practice and during data collection, I often felt disappointed at the nurses' lack of knowledge about dementia. Reflecting on the findings of the study, this disappointment remains. Through focusing on function and talking about individualised care the nurses manage to side step the limits of their knowledge of the scope of dementia. It still seems unbelievable that nurses, who regularly see

people struggle to find words or have continence difficulties, can imagine that it's just an unlucky coincidence that these people also have dementia.

My struggle to understand the gaps in the nurses' knowledge and their limited overview of dementia, perhaps helped me to hear nurses as they told me about their views of the unpleasant nature of dementia. These views seemed to contrast with the trivialising views of other nurses. Only as data collection progressed did it become clear that many nurses understood stigma to be related to dementia and recognised the enormity of the diagnosis. Many of these nurses chose to avoid the use of the word dementia and others stopped making eye contact with me and were clearly uncomfortable. The idea that nurses protect themselves from these feelings, through a variety of manipulations of their language and conceptual understandings, began to emerge. While this process also, disappointingly, limits the nurses' ability to help individuals plan for their future, I was reassured that some nurses at least understood the scope and potential significance of the diagnosis.

As this research process reaches completion I feel that significant developments have been made. The challenge now is to take these new understandings back to the clinical areas and improve the nursing care of people who have dementia.

10.9 Reflection on Research Approach

The use of Bourdieu's theoretical framework in this study has required a reflexive approach throughout the thesis. This final reflective account highlights my own feelings about the research process and nurses' contributions.

This study developed from a real 'burning question' from nursing practice. At this stage, nearing the end of the research process, the question seems so much more

complex than originally anticipated! My expectation of understanding nurses' conceptualisation of dementia and knowing why my nursing colleagues celebrated Sally's diagnosis of vascular dementia seems very unrealistic. Yet the new understandings of nurses' conceptualisations of dementia, developed through this work, do help to make sense of many experiences, interactions and encounters from my own nursing practice and family life.

As a novice researcher, there were anxieties in the research design phase of the study and some 'rookie mistakes' during the data collection. Reviewing the transcripts of interviews and focus groups, it is all too easy to spot probing opportunities which were missed and assumptions about the data which were made. However, overall, the data have been interesting, though at times shocking and have allowed me to explore this complex issue. I have been challenged by nurses' views, appalled by limited knowledge, angered by nurses' attitudes and reassured by some of the most compassionate nursing care that I have ever encountered.

Using Bourdieu's theory as a framework for this work has allowed far greater interrogation of the data that might have been possible otherwise. While the framework was innovative to the point of being unorthodox, it fitted both the research questions and my own approach to research and has offered a great deal in terms of theory development from these data. It has also encouraged a reflexive approach which would, otherwise, have been missing from this work.

Each of the four conceptualisations of dementia presented in this thesis makes sense to me. While I do not concur with each one, I can recognise aspects of each from my own practice and can understand how each conceptualisation could shape nursing care. The limitations inherent in each conceptualisation leave me with concerns and an over-riding feeling of unease about the poor overview that nurses have of the

whole process of dementia. This must surely be the focus of future academic work and practice development.

10.10 Concluding Remarks

This study aimed to explore nurses' conceptualisation of dementia. Four conceptualisations are presented in fulfilment of that aim. These conceptualisations are discussed in relation to care practice and planning, highlighting structural and personal motivations inherent in these understandings of dementia and dementia care. The study findings permit previously unexplored insights into nurses' understandings of dementia and the relationship between those understandings and the care that nurses give. The findings go some way to addressing Sally Thorne's assertion that relationships between nursing practice and conceptual knowledge are ambiguous and confusing (Thorne 2005). Implications for practice and education are highlighted. While the findings of this study have the potential to shape development in dementia nursing, further work is needed in order to improve nurses' knowledge, develop their understanding of the scope of dementia and, subsequently, improve the nursing care of those who live with dementia.

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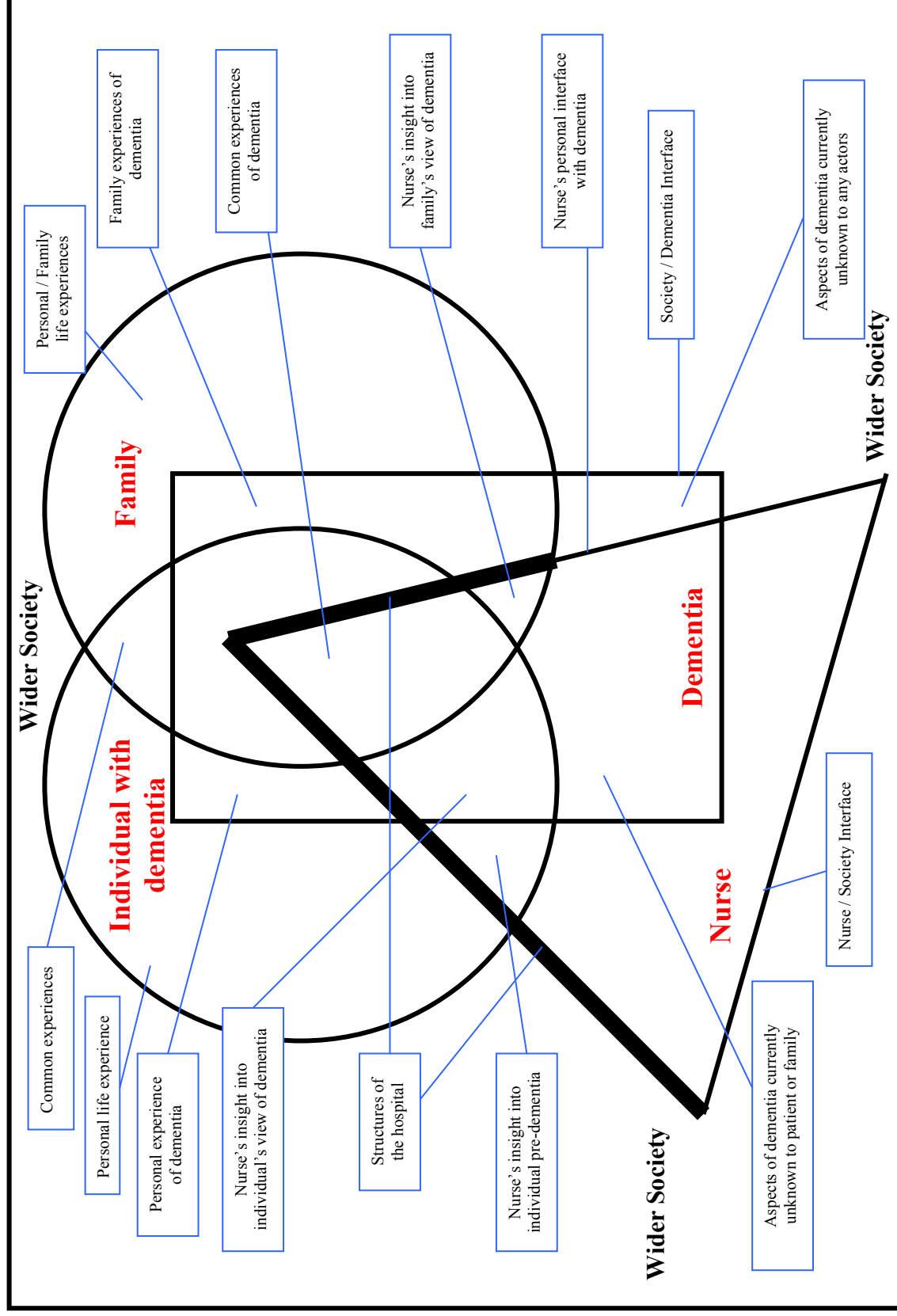
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APPENDICES

APPENDIX ONE

DIAGRAM ONE: TOPOLOGY

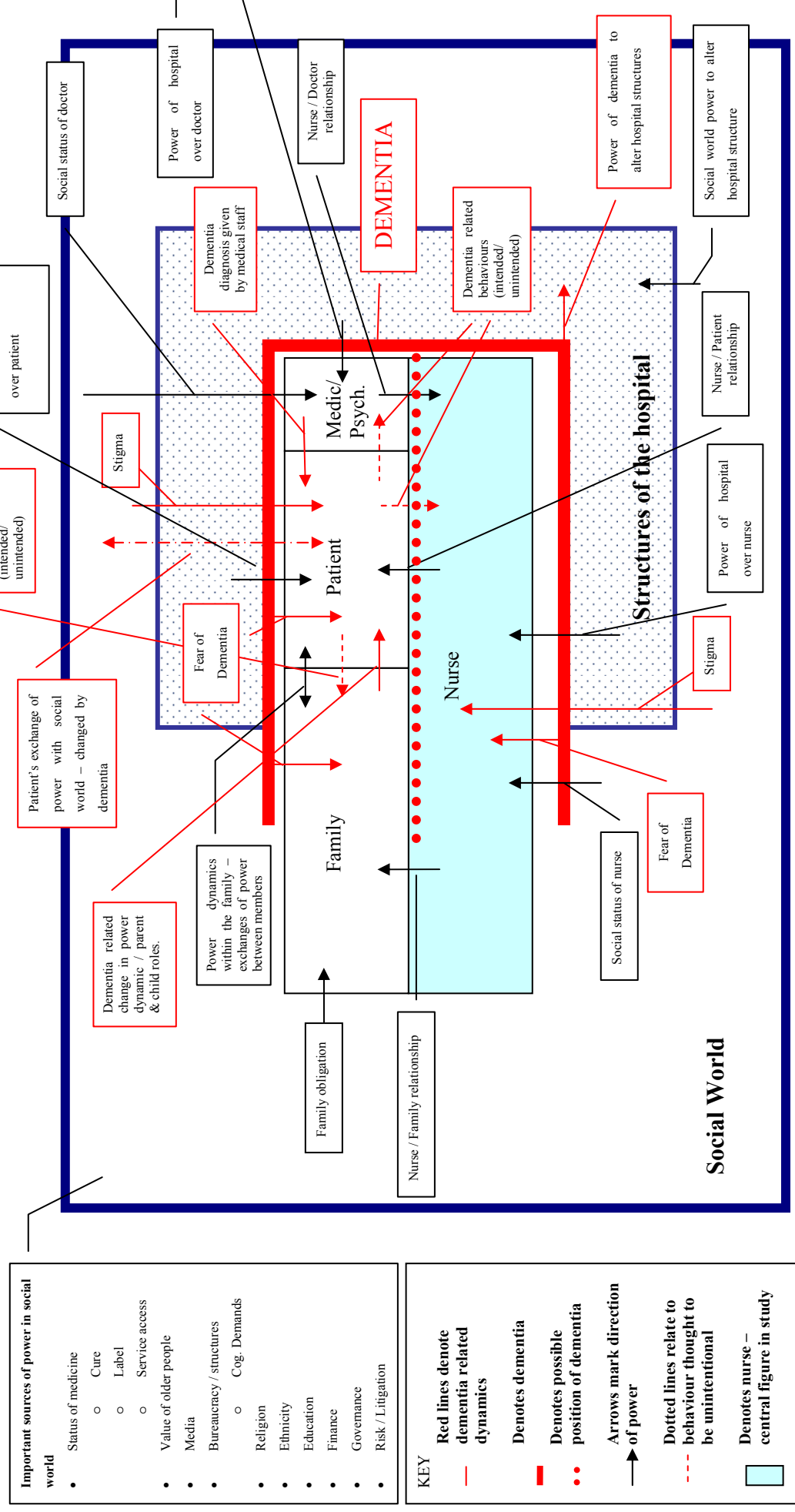
Diagram One: Nurse / Patient / Family / Dementia – A Topology



APPENDIX TWO

DIAGRAM TWO: POWER DYNAMICS OF FIELD AND DATA

Diagram Two - Power Dynamics Evident in Study of the Field and Data



APPENDIX THREE

DIAGRAM THREE: SOCIAL WORLD – INFLUENCES EMERGING FROM DATA

Diagram Three - Social World – Influences Emerging from Data

<ol style="list-style-type: none"> 1. Power of education to shape attitudes to older people 2. Nurse education – deficits / variations / attitudes 3. Educational level of older people - formal education / life experience 4. Influence of education in dementia screening 	<ol style="list-style-type: none"> 1. Secularisation of society 2. Some mismatch between generations in terms of belief / formal religious connections – particularly evident in elderly care 3. Religion impinging on workplace – Christmas / Friday prayers 	<ol style="list-style-type: none"> 1. Risk - litigation in medicine / care areas 2. Risk – can elderly people go home / make decisions 3. Formally detained patients – locked doors etc 	<ol style="list-style-type: none"> 1. Govt introduced healthcare policy / priorities 2. Political agenda in healthcare – ‘sexy’ issues 3. Burden of elderly sound bites & planning 4. Funding of healthcare and elderly care 5. Increased bureaucracy in healthcare and society – increased cognitive demands on older people
Education	Religion	Law	Governance
Ethnicity	Medicine	Economy	Media
<ol style="list-style-type: none"> 1. Influence of ethnicity on attitudes to older people 2. Ethnic diversity of nurses alters ward dynamics and challenges older people 3. Older people – attitudes to ethnic minority staff 4. Influence of ethnicity on dementia screening 	<ol style="list-style-type: none"> 1. Image of medicine in today’s society 2. Status of medicine – mismatch between current generation and older people in terms of attitude to medicine 3. Power of medicine within society – validating ill health – sick lines / disease labels / gatekeeper to services 	<ol style="list-style-type: none"> 1. Economy of healthcare 2. Finances of older people in general – selling houses to pay for care etc 3. Specific issues eg NHS continuing care can lead to excess disability 4. Funding of hospitals / improvements / staffing 	<ol style="list-style-type: none"> 1. Image of the elderly portrayed on film / TV / print media 2. Value attached to older people and process of ageing – portrayed to population at large

APPENDIX FOUR

CONTRIBUTING NURSES' AND CHARGE NURSES' PROFILES

Contributing Nurses' And Charge Nurses' Profiles

Nurse's Name	Study Setting	Data Collection Method	Reg.	Experience / Position / Comments
Alice	Ac. Med	Focus Gp	RN	1yr in medical ward.
Alison	Ac. Med	Interview	RN	7yrs (part time) medical experience
Andrea	Eld Med	Focus Gp	RN	15yrs + experience. Enrolled nurse converted to RN.
Angela	Rehab	Interview	RN/ RMN/ M/W	30yrs + experience. Wide range of experience. Never worked as RMN. Nearing retiral
Asif	Ac. Med	Interview	RN	3yrs experience. Previous care work in Pakistan
Ava	Eld Med	Focus Gp	RN	4yrs experience. (2 nd career)
Carol	Eld Med	Interview	RN	12yrs + experience C/N Originally Enrolled Nurse, converted to RN 6yrs ago.
Carrie	Ac. Med	Focus Gp	RN	10yrs. Recently returned to day duty after long spell on nights
Catherine	Eld Med	Focus Gp	RN	10yrs experience. Enrolled nurse converted to RN.
Emily	Ac. Med	Interview	RN	9yrs experience in same ward.
Felicity	MH CC	Focus Gp	RN/ RMN	15yrs experience. 8yrs as RMN
Flora	Rehab	Interview	RN	12yrs experience. Mostly as enrolled nurse. Lots of time in cont. care & learning disabilities
Francis	Ac. MH	Interview	RN/ RMN	C/N Works in acute area but also responsible for cont. care wards. Recent secondment to cont. care to pilot new education initiative.

Helen	Eld Med	Focus Gp	RN	4yrs experience. (2 nd career) Part time.
Jim	MH CC	Focus Gp	RMN	6yrs as RMN after career in army.
Joanne	Ac. MH	Focus Gp	RMN	10yrs. Never worked in cont. care always acute wards.
June	Ac. Med	Interview	RN	10 yrs in medical wards including some cont. care experience
Lauren	MH CC	Interview	RMN	4yrs experience. Mostly in cont. care.
Leanne	Ac. Med	Interview	RN	3yrs medical and surgical experience
Louise	Ac. Med	Focus Gp	RN	Recent recruit
Lynsey	Ac. MH	Focus Gp	RMN	1yr as RMN
Margaret	Eld Med	Focus Gp	RN	Recent recruit from abroad.
Marjorie	Ac. Med	Interview	RN/ RMN	15yrs + mainly worked as RN. Range of experience
Maria	MH CC	Interview	RN/ RMN	8yrs experience in Psych. Started in cont. care. Left for experience in acute psychiatry but returned recently.
Mary	Eld Med	Focus Gp	RN	15yrs + experience. Nearing retiral.
Melanie	Ac. Med	Focus Gp	RN	3yrs experience. Recently come to acute medicine from surgical
Moira	MH CC	Interview	RN/ RMN	15yrs + experience. Worked in cont. care for 10yrs. Working on Dementia Diploma.
Molly	Ac. Med	Interview	RN	20yrs+ Enrolled nurse converted to RN. Lots of night shift experience
Norman	Eld Med	Focus Gp	RN	Recent recruit from abroad.
Pat	Ac. MH	Focus Gp	RN/ RMN	17yrs experience. Mostly as RMN.
Penny	Eld Med	Focus Gp	RN	3yrs experience.

Pete	Rehab	Interview	RN	3yrs experience. Previous work as carer in dementia unit after leaving army
Samantha	Ac. Med	Focus Gp	RN	3yrs experience. studying for diploma to degree conversion
Simon	MH CC	Focus Gp	RMN	8yrs. Has done acute psychiatry but returned to cont. care
Susan	Eld Med	Interview	RN	15yrs + experience C/N Chose to take on ward for 'confused older people' in recent restructure
Steven	MH CC	Interview	RMN	5yrs Mainly experienced in acute psychiatry. New to cont. care
Theresa	MH CC	Interview	RN/ RMN	18 yrs + C/N Works only in cont. care. Refuses to cover acute areas. Uses RN procedural skills throughout cont. care areas. Employed as RMN.
Victoria	Ac. Med	Interview	RN/ RMN	12yrs experience. 6 yrs abroad. 2yrs as RMN.

Glossary

Eld. Med	Medical unit specifically for older people. Typically less acute than general units and with longer lengths of admission.
Rehab	Rehabilitation unit for older people. Focus on rehabilitation post stroke or following lengthy medical admission.
Ac. Med	Acute medical unit. Busy units. Focus on older people. Typically shorter lengths of admission. Sometimes transfer patients to Elderly Medical or Rehabilitation units prior to discharge.
Ac. MH	Acute Mental Health – acute admissions or assessment units. Some settings were specifically for older people. Others were general units.
MH CC	Mental Health continuing care – long stay environment for older people. Mainly people living with dementia but some with other mental health problems.

APPENDIX FIVE

INFORMATION, CONSENT FORMS & TOPIC GUIDES

Nurses' Information Sheets

Focus Group and Observation

Interview and Observation

Patient Information Sheet

Relative / Visitor Information Sheet

Nurses' Consent Forms

Focus Group and Observation

Interview and Observation

Patient Consent Form

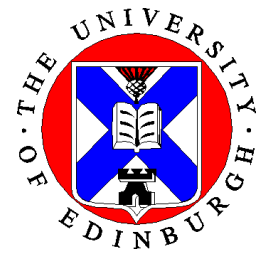
Notification of Involvement in a Research Project – Entry for Medical Records

Poster

Focus Group Guide

Interview Guide

Observation Guide



Dementia Nursing Project Information Sheet For Nurses

I would like to invite you to take part in a research project. It is important that you read and understand the following information about the project before you decide whether or not to take part. Please take time to read the information below and to discuss it with colleagues if you wish. Please feel free to ask me any questions that you have after reading the information sheet. You can contact me either while I am on the ward or using the contact details below.

The Dementia Nursing Project

- The Dementia Nursing Project aims to find out how nurses think about dementia and how this relates to their day to day practice.
- You have been asked to take part as a nurse working with people who have dementia.
- You are under no obligation to participate in the Project. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw at any time and without giving a reason. Your decision regarding this project in no way affects your position within your place of work.

What happens if I decide to take part?

- The Project will gather data through focus groups, observation and interviews. You are being asked to participate in the focus group and observation sections.
- **Focus Groups** - As a nurse you will be asked to discuss your own thoughts and feelings about dementia in a group of nurses from your own clinical area. The group session will be entirely confidential. The session will be recorded for the exclusive use of the researcher and the tapes will be destroyed at the conclusion of the Project. The groups will be held at a time suitable to the Charge Nurse and will last between 45mins – 1 hour.
- **Observation** – The researcher will undertake periods of observation in the ward area in order to ensure that the reality of caring for people with dementia is reflected in the findings of the Project. During these periods the researcher will watch, from a distance, what happens in the ward. Nurses will not be identified and the researcher will not focus on individual care practices. In line with best practice recommendations consent for the observation will be sought from both nurses and patients. Patient confidentiality will be assured.
- **Feedback Sessions** - Finally, a focus group will be held to allow the provisional findings of the study to be discussed with the nurses who have participated.

What are the potential disadvantages of taking part?

- The focus group sessions are intended to be very relaxed and enjoyable. However, it is possible that discussing thoughts and feelings about dementia could upset some participants. Information will be given to all participants about where to find support or advice in the event of such distress. Any participant who feels unable to continue may leave the group at any time.
- The focus group sessions are confidential. It will, therefore, not be possible for participants to talk about what was discussed after the focus group ends.
- As a nurse you may feel uncomfortable being observed with patients in certain situations. For example, if a patient is upset. The researcher will try to be sensitive to such situations. However, if at any time you feel uncomfortable please feel free to ask the researcher to move away from the situation.

What are the potential benefits of taking part?

- It is not expected that there will be any immediate benefits to participants in the Project. However, it is anticipated that the focus groups will stimulate interesting discussion and will be an enjoyable experience.
- In the longer term it is hoped that nursing care of people with dementia may be more fully understood as a result of this study.

Further information about the Dementia Nursing Project

- It is anticipated that the findings of this study will be reported in mainstream nursing and more specialised dementia journals.
- The Project will be carried out by a single nurse researcher as part of her PhD studies. Experienced researchers from the School of Nursing Studies, University of Edinburgh are supervising the work.
- The work is funded by the Gardner Bequest, a scholarship administered through the University of Edinburgh School of Nursing Studies.
- The Dementia Nursing Project has been reviewed by the Lothian Health Research Ethics Committee.

Thank you for taking the time to read this Information Sheet. If you require further information please do not hesitate to contact – Sarah Rhynas, Postgraduate Research Student, School of Nursing Studies, University of Edinburgh, 12 Buccleuch Place, Edinburgh, EH8 9JT, Tel. 0131 650 4272, Email S.J.Rhynas@sms.ed.ac.uk



Dementia Nursing Project Information Sheet For Nurses

I would like to invite you to take part in a research project. It is important that you read and understand the following information about the project before you decide whether or not to take part. Please take time to read the information below and to discuss it with colleagues if you wish. Please feel free to ask me any questions that you have after reading the information sheet. You can contact me either while I am on the ward or using the contact details below.

The Dementia Nursing Project

- The Dementia Nursing Project aims to find out how nurses think about dementia and how this relates to their day to day practice.
- You have been asked to take part as a nurse working with people who have dementia.
- You are under no obligation to participate in the Project. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw at any time and without giving a reason. Your decision regarding this project in no way affects your position within your place of work.

What happens if I decide to take part?

- The Project will gather data through focus groups, observation and interviews. You are being asked to participate in the interview and observation sections.
- **Interview** - As a nurse you will be asked to discuss with a nurse researcher your own thoughts and feelings about dementia and care of people with dementia in your own clinical area. The interview will be entirely confidential. It will be recorded for the exclusive use of the researcher and the tapes will be destroyed at the conclusion of the Project. The interview will be held at a time suitable to you.
- **Observation** – Periods of observation in the ward area will be undertaken in order to ensure that the reality of caring for people with dementia is reflected in the findings of the Project. During these periods the researcher will watch, from a distance, what happens in the ward. The researcher hopes to gain an insight into care practices and interaction with people who have dementia. Nurses will not be identified and the researcher will not focus on individual care practices. In line with best practice recommendations consent for the observation will be sought from both nurses and patients. Patient confidentiality will be assured.

What are the potential disadvantages of taking part?

- The interview is intended to be very relaxed. However, it is possible that discussing thoughts and feelings about dementia could upset some participants. Information will be given to all participants about

where to find support or advice in the event of such distress. Any participant who feels unable to continue may terminate the interview at any time.

- The interviews are confidential. It will, therefore, not be possible for participants to talk about what was discussed after the interview.
- As a nurse you may feel uncomfortable being observed with patients in certain situations. For example, if a patient is upset. The researcher will try to be sensitive to such situations. However, if at any time you feel uncomfortable please feel free to ask the researcher to move away from the situation.

What are the potential benefits of taking part?

- It is not expected that there will be any immediate benefits to participants in the Project. However, it is anticipated that the interviews will stimulate interesting discussion and will be an enjoyable experience.
- In the longer term it is hoped that nursing care of people with dementia may be more fully understood as a result of this study.

Further information about the Dementia Nursing Project

- It is anticipated that the findings of this study will be reported in mainstream nursing and more specialised dementia journals.
- The Project will be carried out by a single nurse researcher as part of her PhD studies. Experienced researchers from the School of Nursing Studies, University of Edinburgh are supervising the work.
- The work is funded by the Gardner Bequest, a scholarship administered through the University of Edinburgh School of Nursing Studies.
- The Dementia Nursing Project has been reviewed by the Lothian Health Research Ethics Committee.

Thank you for taking the time to read this Information Sheet. If you require further information please do not hesitate to contact – Sarah Rhynas, Postgraduate Research Student, School of Nursing Studies, University of Edinburgh, 12 Buccleuch Place, Edinburgh, EH8 9JT , Tel. 0131 650 4272, Email S.J.Rhynas@sms.ed.ac.uk

Nursing in Elderly Care – an Exploratory Study

Information Sheet for Patient



I am a nurse and a student at the University of Edinburgh where I am carrying out a study about nurses who care for elderly people. I am particularly interested in how nurses look after people who sometimes have problems with their memory. The study will explore how nurses think about elderly people and how this relates to what they do in their work.

The ward where you are at the moment is part of the study. I am writing to you to ask if you would be willing to take part in the research project.

Please read the information below before you decide whether or not to take part. Your care will not be affected by your decision.

About the study

I will visit the ward two or three times over the next week or two. During my visits I will observe the nurses as they speak to patients and carry out their work. I will also make some notes to refer to later. While I am around the ward I might speak to you but I will not be part of your care. I will not observe any care or conversations that should be private. If you do not wish me to be around at any time you are welcome to ask me to leave, or to tell your nurse that you don't want me to be there. I expect that sometimes this will happen and I will not be offended!

Privacy

It is important that your privacy is assured. I will not record anything electronically but I will make a few notes. If I publish any information from the study I will not use your name or the name of the ward. All my notes and information will be kept in a locked cupboard for only my use.

I hope that the information I have given you will help you to decide about the study. If you would like to know anything else please feel free to ask me. You might want to speak to your family or friends before you decide whether or not to take part. It is important that you understand that;

- You are free to change your mind at any time and without giving a reason.
- Your decision will not affect your care in the ward in any way.

Thank you for reading this information. If you would like to speak to me about the study please contact me either by phone or when I come to the ward.

Sarah Rhynas, School of Nursing Studies, 12 Buccleuch Place, Edinburgh, 0131 650 4272

Nursing in Elderly Care – an Exploratory Study

Information Sheet for Relatives & Visitors



I am a nurse and a student at the University of Edinburgh where I am carrying out a study about nurses who care for elderly people.

I am particularly interested in how nurses look after people who sometimes have problems with their memory. The study will explore how nurses think about elderly people and how this relates to what they do in their work. The ward that you are visiting is part of the study. I have written to your relative/friend to ask if they would be willing to take part in the research project. The information below is provided in order

that you are fully informed about the study being undertaken on the ward.

About the study

I will visit the ward two or three times over the next week or two. During my visits I will observe the nurses as they speak to patients and carry out their work. I will also make some notes to refer to later. While I am around the ward I might speak to your relative/friend but will not be part of the care team. I will not observe any care or conversations of an intimate nature. The focus of the observation is the nurse and your relative/friend will only be observed in association with his/her nurse. On every visit I will introduce myself and explain why I am visiting the ward. I will also ask your relative/friend for permission to observe on that day. Since every day is different I will only observe your relative/friend if they agree on that particular day. If at any time they do not wish me to be present they are welcome to ask me to leave, or to tell the nurse that they do not want me to be there. This in no way affects the care.

Confidentiality

It is important that confidentiality is assured. I will not record anything electronically but I will make a few notes. If I publish any information from the study I will not use the name of the individual or the ward. All information will be kept in a locked cupboard for only my use.

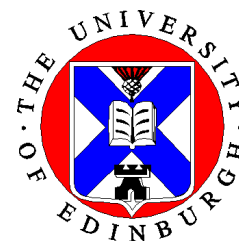
Your relative/friend has met me and has also received an information sheet. They may choose to talk to you about the study. I hope that this information will be sufficient to inform you of the planned research. However, if you would like any further information please do not hesitate to contact me at any time. Thank you for reading this information.

Sarah Rhynas, Postgraduate Research Student, School of Nursing Studies, 12 Buccleuch Place, Edinburgh, 0131 650 4272, Email - S.J.Rhynas@sms.ed.ac.uk

Dementia Nursing Project

Focus Group & Observation Consent Form

Researcher – Sarah Rhynas



Please initial

- I have read and understood the information sheet about the Dementia Nursing Project and have had adequate opportunity to ask questions. ☐
- I understand that my participation is voluntary and I am free to withdraw from the Project at any time ☐
- I agree to the tape recording and subsequent transcription of the focus group sessions in order to facilitate the analysis of the data generated in the group. ☐
- I understand that the tape recordings will only be heard by the researcher or research supervisors and will be destroyed at the end of the project. ☐
- I understand that any quotations from the focus group sessions, used by the researcher in her written accounts of the research, will be fully anonymised. ☐
- I understand that the focus group sessions are confidential and should not be discussed outwith the group except for their presentation as part of reports or papers from the study where they will be fully anonymised. ☐
- I agree to the observation of my nursing practice as part of the general ward observation taking place as part of the Project. ☐
- I understand that individual nurses' names will not be related to observations made and patient confidentiality will be assured. ☐
- I agree to take part in the Dementia Nursing Project.

Signed _____ **(Participant) Date**

Print _____

Signed _____ **(Researcher) Date**

Dementia Nursing Project

Interview & Observation Consent Form

Researcher – Sarah Rhynas



Please initial

- I have read and understood the information sheet about the Dementia Nursing Project and have had adequate opportunity to ask questions. ☐
- I understand that my participation is voluntary and I am free to withdraw from the Project at any time ☐
- I agree to the tape recording and subsequent transcription of the interview in order to facilitate the analysis of the data generated through discussion. ☐
- I understand that the tape recordings will only be heard by the researcher or research supervisors and will be destroyed at the end of the project. ☐
- I understand that any quotations from the interview, used by the researcher in her written accounts of the research, will be fully anonymised. ☐
- I understand that the interviews are confidential and will not be discussed outwith the interview itself except for their presentation as part of reports or papers from the study where they will be fully anonymised. ☐
- I agree to the observation of my nursing practice as part of the general ward observation taking place as part of the Project. ☐
- I understand that individual nurses' names will not be related to observations made and patient confidentiality will be assured. ☐
- I agree to take part in the Dementia Nursing Project.

Signed _____ **(Participant) Date** _____

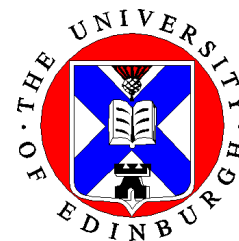
Print _____

Signed _____ **(Researcher) Date** _____

Nursing in Elderly Care – an Exploratory Study

Observation Consent Form

Researcher – Sarah Rhynas



Please initial

- I have read and understood the information sheet about Nursing in Elderly Care – an Exploratory Study and have had the opportunity to ask questions. ☐
- I understand that my participation is voluntary and I am free to withdraw from the Study at any time. ☐
- I agree that the researcher will watch from a distance as the nurses talk to me and works with me on the ward. ☐
- I understand that I can ask the researcher to leave or tell a nurse that I do not want the researcher to observe me anymore. I can do this at any time. ☐
- I understand that the researcher may make some notes but my name will not be related to observations made and my confidentiality will be assured. ☐
- I understand that the researcher will only discuss her observations with her research supervisors and any reference to observations presented as part of reports or papers from the study will be full anonymised. ☐
- I agree to take part in Nursing in Elderly Care – an Exploratory Study. ☐

Signed

(Participant) Date

Print

Signed

(Researcher) Date

Notification of Involvement in a Research Project

For Entry in Patient Medical Records

The Dementia Nursing Project

Researcher – Sarah J. Rhynas



..... (patient name) has agreed that interactions between him/herself and members of the ward nursing staff can be observed as part of the Dementia Nursing Project (Nursing in Elderly Care – Exploratory Study). An information sheet about the study has been left with the patient for reference and a further copy has been left at the bedside for the information of relatives and significant others. Verbal informed consent has been obtained by myself today and will be sought prior to any further contact with the above named patient. The focus of this study is the nurse. The patient's name will not be used in connection with this study. No recording equipment has been used during this observation of nurses' interactions with the above named patient.

Signed Date

Sarah J. Rhynas (Researcher)

For Further Information about the Dementia Nursing Project please contact;

Sarah J. Rhynas
PhD Student
School of Nursing Studies
University of Edinburgh
12 Buccleuch Place
Edinburgh
0131 650 4272
S.J.Rhynas@sms.ed.ac.uk



Nursing in Elderly Care – Exploratory Study



My name is Sarah Rhynas and I am a nurse and a research student at Edinburgh University. I am currently carrying out some research here so you might see me about the ward from time to time. If either you or your relatives & friends have any questions about the study, please feel free to contact me either when I'm on the ward, or using the details below.

Sarah Rhynas, Postgraduate Research Student, School of Nursing Studies, University of Edinburgh, 12 Buccleuch Place, Edinburgh, Tel. 650 4272, Email S.J.Rhynas@sms.ed.ac.uk

Focus Group Topic Guide

Personal introduction, outline of research project and confidentiality issues.

Ensure consent & start tape

- **Some of you may have personal experience of dementia or may know a bit about dementia from life outside the hospital. Can you tell me what you personally understand by the word dementia? (newly inserted after FG 2 – try personal first before getting into professional / work issues)**

- **How do your personal views relate to those that you use in your work?**
- **What do you understand by the term ‘dementia’?**

(very general exploratory discussion)

- Symptoms
- Social aspects
- Life changing aspects
- Personality

- **How did these ideas about dementia develop?**
- Were you taught about it, or did you develop ideas through your work with people?
- What was the main influence in determining how you think about dementia?
- What kinds of resources are available to help you to find out more about dementia?
- **Does a diagnosis of dementia influence the way that you care for a pt on the ward?**
- What about at the time of discharge, are plans influenced by a diagnosis of dementia?
- Are plans about care made with the dementia in mind?
- Do you think about the possibility of dementia progression when you plan future care?
- How might the dementia progress and what kind of probs might be ahead? (post FG1)
- How do you deal with patients wandering on the ward?
- **Does the dementia change the way that you speak to an individual, or what you would speak to them about?**

- Would you speak to a patient about dementia?
- Does the ward use any tools to help you interact with person who has dementia?
- Is there anything that you think that you don't do or don't do well enough in your workplace which would be good to try or improve? (added after FG3)

Risk (added after FG1)

- Is risk a big consideration for you when caring for dementia patients?
- Discharge? Mobility? Absconding? Professional liability?

Personal Responses (added post FG1)

- How do you feel when you're asked the same question repeatedly by a patient?
- ?frustration ?angry
- If a patient asks for one particular item repeatedly would you fulfil the same request over and over? For example, if a patient asks for tea and biscuits three times in the space of an hour what would you do?
- Why would you give / not give the tea?
- What else might you try?
- How do you feel about looking after patients who have dementia?

Reflecting on Patient's Biography (added post observation)

- Do you ever think about what your patient was like prior to the dementia? Job? Family?
- How does that help you in your work with that patient?

Items to pursue if they come up;

- Confusion / dementia / pleasantly confused
- Quality of life
- Come to terms
- Humour
- Knowledge of scope / symptoms
- Palliative care

Interview Topic Guide

Personal introduction, outline of research project and confidentiality issues.

Ensure consent & start tape

- **Some of you may have personal experience of dementia or may know a bit about dementia from life outside the hospital. Can you tell me what you personally understand by the term dementia?**

- Where did these ideas develop?
- Family members?
- **How do your personal views relate to those that you use in your work?**

In your work as a nurse you care for people who have dementia. What do you understand by the term ‘dementia’? What are your expectations?

(‘If you are told to expect a new admission and it is an 80 year old with dementia what might you expect?’)

- Symptoms
- Social aspects
- Life changing aspects
- Personality

- **How did these ideas about dementia develop?**

- Were you taught about it, did you develop these ideas through your work with people?
- What was the main influence in determining how you think about dementia?
- What kinds of resources are available to help you to find out more about dementia?

- **Does a diagnosis of dementia influence the way that you care for a pt on the ward?**

- What about at the time of discharge, are plans influenced by a diagnosis of dementia?
- Are plans about care made with the dementia in mind?
- Do you think about the possibility of dementia progression when you plan future care?
- How might the dementia progress and what kind of problems might be ahead?
- How do you deal with patients wandering on the ward?

- **Does the dementia change the way that you speak to an individual, or what you would speak to them about?**
- Would you speak to a patient about dementia?
- Does the ward use any tools to help you interact with a person who has dementia?
- Is there anything that you think that you don't do or don't do well enough in your workplace which would be good to try or improve?

Risk

- Is risk a big consideration for you when caring for dementia patients?
- Discharge? Mobility? Absconding? Professional liability?

Personal Responses

- How do you feel when you're asked the same question repeatedly by a patient?
- ?frustration ?angry
- If a patient asks for one particular item repeatedly would you fulfil the same request over and over? For example, if a patient asks for tea and biscuits three times in the space of an hour what would you do?
- Why would you give / not give the tea?
- What else might you try?
- How do you feel about looking after patients who have dementia?

Reflecting on Patient's Biography

- Do you ever think about what your patient was like prior to the dementia? Job? Family?
- How does that help you in your work with that patient

Items to pursue if they come up;

- Confusion / dementia / pleasantly confused
- Quality of life
- Come to terms
- Humour
- Knowledge of scope / symptoms
- Palliative care

Observation Guide

First Visit

- Initial impression
- Ward routine
- Organisation – layout, staffing
- Position for observation
- Notes on culture of the place, rules, ‘feel’ of ward – relaxed, busy, chaotic, acute
- Shift pattern established to ensure cover all day with observation

Second & Subsequent Visits

- Interaction between patients
- Interaction between staff and patients
- Interaction between those with and without dementia
- Interaction between staff and family

- Recognition of dementia by staff

- Strategies in place;
- Falls prevention – traffic lights / hip pads
- Nutrition
- Story books
- Biography charts / family feedback
- Wanderguard
- Wall murals
- ‘meeting places’

- Constraints on staff
- Staffing
- Organisation
- Skill mix
- Language
- Acuity

- Ward layout
 - Leadership
 - Medical / psych input – constraint or empowering?
 - Attitudes
-
- Differences in ward at different times
 - Differences between staff
-
- Compassion
 - Caring attitude
 - Examples of ‘care’
-
- Any unique aspects?
-
- Anything you’d like to take with you?
-
- Anything you’d like to change
 - Why??